# ‘Them Two Things Are What Collide Together’:

# Understanding the Lived Experiences of Lesbian, Gay, Bisexual and/or Trans People Labelled with Intellectual Disability

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## Introductory Chapter: Thesis Overview

The voices of people labelled with intellectual disabilities (ID) who are non-heterosexual are often unheard in both clinical practice and the research literature. Much of their lives are therefore hidden (Abbott & Howarth, 2005). Previous research has been over narrated by family, carers and professionals, with little input from people labelled with ID. Findings of previous studies have been inconsistent and suggested: that some people who engage in same-sex sexual behaviour identify as heterosexual (Thompson, D., 1994), that sexual identity has a context dependent fluidity where people may continuously change the labels they use (Thompson, S.A., 2002), or that people routinely use labels such as lesbian, gay, and bisexual (Abbott & Howarth, 2005). Studies involving people labelled with ID talking about their experiences tend to be ten or more years old, with some being much older. The socio-cultural and political climate has evolved over this time period, with more legally protected equality for minority groups than ever before. Little is known about how people currently experience their identities, however, and whether they have felt any benefits of cultural and legislative changes. Understanding what people think and feel about their sexual identities has clinical implications for therapists and for informing psychologically supportive systems of care. The best available evidence on which policies and guidance are based might not accurately reflect people's current experiences and their clinical need. The general aim of this project is therefore to foreground the voices of people labelled with ID who are non-heterosexual, in order to add to new understandings to the existing research evidence base.

Interest in the broad research topic of sexual identity developed as a result of the researcher's personal reflections on his own experiences of coming out as gay. The

narrower focus of the project is on lesbian, gay, bisexual, and/or trans (LGBT) identities in people labelled with intellectual disabilities (ID). This focus evolved through a combination of factors: wider reading of the psychological literature for identified yet currently underexplored issues in sexuality research; growing awareness of challenges faced by people labelled with ID, through conversations with potential research supervisors and clinical teaching units; and a personal interest in issues of equality and rights to freedom of expression, which are also clinically relevant issues for people labelled with ID. The overall aim of the project is an exploration of the lived experiences of lesbian, gay, bisexual and/or trans (LGBT) people labelled with intellectual disabilities (ID). The project is reported in two chapters.

Chapter one is a report of a systematic review of qualitative research literature exploring first-person accounts of sexual identities in lesbian, gay, bisexual and/or trans (LGBT) people labelled with intellectual disabilities (ID). Compared with service user voices, staff and family views were often over represented in the literature, however, a sufficient number of retrieved studies were eligible for inclusion in the review. Included studies dated from the previous twenty years with few recently published studies. Results were reported in a narrative summary. More interpretative syntheses would have been inappropriate given the limitations of the data. Key findings suggested that people labelled with ID who had same-sex attractions had mixed experiences of sexual identities. Further qualitative research was suggested to explore how people might experience their sexual identities in the current socio-political climate.

Chapter two reports on an original empirical study conducted with a sample of LGBT-identified people labelled with ID. The main research question followed the theme of chapter one: how do people labelled with ID who are LGBT experience their sexual

identities? IPA methodology was felt to be the most appropriate approach for this study as IPA privileges an individual's unique experiences through in-depth analysis. The position and effect of the researcher is considered an important aspect of IPA research, which felt significant given the researcher's own sexual identity experiences. Participants were recruited via a support group for people labelled with ID who are LGBT. Participants therefore had access to LGBT-specific support, which offered a unique opportunity for the researcher to explore their experiences of sexual identities and coming out process in the context of an LGBT-affirmative environment. Key findings from data analysis suggested that participants had well established ideas about their identities and disclosed LGBT labels (or 'come out') to some people. In abusive environments some people made active decisions about what information felt safe to share, resulting in not coming out to everyone. A key clinical implication of the study is participants' need for holistic services to support them with their ID and LGBT needs simultaneously. Qualitative research is suggested which included further exploring the clinical implications of the coming out processes described by participants.

## References

Abbott, D., & Howarth, J. (2005). *Secret loves, hidden lives?: exploring issues for people with learning difficulties who are gay, lesbian or bisexual*: The Policy Press.

Thompson, D. (1994). Sexual experience and sexual identity for men with learning disabilities who have sex with men. *Changes-Sheffield, 12*, 254-254.

Thompson, S. A. (2002). *Disabling sexualities: an exploratory multiple case study of self-identified gay and bisexual men with developmental disabilities.* (NQ75093 Ph.D.), The University of British Columbia (Canada), Ann Arbor. Retrieved January 2014, from http://search.proquest.com/docview/305430513?accountid=12117

# Chapter 1: Literature Review[1]

## A Systematic Review of Qualitative Research Reporting the First-Person Accounts of People with Non-Heterosexual Identities Labelled with Intellectual Disabilities

[1]Article prepared for submission to Journal of Applied Research in Intellectual Disabilities for peer review. Please see Appendix A for author guidelines. Please note that these guidelines differ from APA publication guidance. Initials in in-text citations are given for authors Thompson, D., and Thompson, S.A., for clarity.

**Abstract**

*Background.* Research involving people labelled with intellectual disabilities (ID) has presented inconsistent findings about whether people relate to 'a sexual identity' or engage in sexual behaviours without labels. The current study aimed to systematically review available qualitative literature reporting first-person narratives of lesbian, gay, bisexual and trans (LGBT) identities.

*Methods.* Twelve eligible studies were included and quality appraised. Authors' key themes were presented in a narrative summary.

*Results.* Diverse LGBT identities were reported. Distress prior to coming out was relieved with positive responses. Support needs were communicated but often unheard by services. Distress may be avoidable with proactive support. Gaps in current knowledge were highlighted including the experiences of lesbians and trans people labelled with ID, and those who have had (or continue to have) same- sex sexual contact and identify as heterosexual.

*Conclusions.* More qualitative research is needed to expand the evidence base and inform interpretative syntheses of findings.

*Keywords:* lesbian, gay, sexuality, identity, narrative summary, systematic review

## Introduction

Myths still exist which deny people labelled with intellectual disabilities[2] (ID) any sexuality, assume heterosexuality or pathologise sexual identities (Thompson, Bryson, & De Castell, 2001; Cambridge & Mellan, 2000). Historically, ID was inextricably linked with deviancy, and understood as "both cause and effect of sexual 'vice'" (Kempton & Kahn, 1991, p.95). It was

common for people labelled with ID to live in large institutions where potential for opposite-sex sexual contact was intentionally restricted via single-sex segregation where sexual needs were largely ignored (Kempton & Kahn, 1991). Given that the eugenics movement of the early twentieth century was responsible for the non-consensual sterilisation of tens of thousands of people labelled with ID (Kempton & Kahn, 1991), it is unsurprising that societal negative attitudes towards sex between people labelled with ID informed such segregation; a major feared outcome was procreation, and the difficulties associated with experience of ID were considered to be hereditary. Same-sex segregation implied an assumption of heterosexuality, denial of non-heterosexuality, or that same-sex sexual contact necessitated fewer restrictions than opposite-sex sexual contact, where ending the heredity of ID was paramount.

In the following decades, the normalisation principle (Nirje, 1969; 1994) influenced a shift in attitudes concerning how people labelled with ID might live more meaningful and 'normal' lives in community environments rather than institutions. Wider recognition of the prevalence of sexual abuse experienced by people labelled with ID, the advent and fear of AIDS/HIV in the 1980s and increasing acknowledgement of some of the sexual needs of people labelled with ID prompted greater provision of sex education (Kempton & Kahn, 1991). In the UK, however, 'Section 28' of the Local Government Act 1988 prevented the 'promotion' of homosexuality in schools, thus denying young non-heterosexual people labelled with ID (or those questioning their sexualities) the opportunity for sex education appropriate to their needs; the legislation was not amended in England until 2003 (Section 122 of the Local Government Act 2003). In summary, sexual expression for people labelled with ID has historically been associated with negative attitudes and oppression.

Legislation such as the Human Rights Act 1998, Mental Capacity Act 2005, and Equality Act 2010, now protect some of the rights of people labelled with ID and those who are lesbian, gay, bisexual, and/or trans (LGBT). UK Government strategies (Valuing People, DH, 2001; Valuing People Now, DH, 2009) highlighted sexuality as a key target area for improving standards of support for people labelled with ID, yet there has been slow progress and a gap exists between recommendations set out in such policies and the daily experiences of people labelled with ID (Joint Committee on Human Rights, JCHR, 2008). Adults labelled with ID are vulnerable to not having their human rights respected, they may be less aware of their rights when these have been infringed, and fear that they would not be believed if they reported rights abuses or crimes against them (JCHR, 2008). Legislation and policies intended to protect and promote equality and valued living for people labelled with ID are clearly not easy to translate into meaningful and sustainable practice. Much of the research on which policies are based pre-date legislative changes, the significance of which has yet to be investigated. The lack of research exploring the experiences of people living with an ID label (Beail & Williams, 2014) and significant gaps in knowledge about those who are LGBT (Abbott & Howarth, 2007) might account for some of the difficulties in translating policies into practice.

Staff who assist people labelled with ID in accessing sex education can have mixed opinions as to its appropriateness, with some expressing more negative attitudes towards same-sex sexuality than heterosexuality (Swango-Wilson, 2008). People labelled with ID are rarely asked about their sexual needs by those who support them, services for people labelled with ID often do not proactively facilitate discussion or promote awareness of sexuality, and, where they do the focus is usually heterocentric (Abbott & Howarth, 2007; Thompson, Bryson & De Castell, 2001). Few staff who are LGBT are 'out' (have disclosed

their non-heterosexual sexuality) to service users (Abbott & Howarth, 2005; Valios, 2002). This could deny people labelled with ID access to otherwise available positive role models (Noonan & Taylor Gomez, 2011). Consequently, people labelled with ID who are LGBT might experience barriers in the development and expression of their sexualities and identities.

Previous research has presented inconsistent findings in how people label their sexual identities. Some reported that people self-defined as lesbian, gay or bisexual (Abbott & Howarth, 2005), while others found that some people struggled to define their sexualities or preferred not to use labels (Withers, 1997), with others reporting some men who routinely had sex with men identified as heterosexual (Thompson, D., 1994). Variation in how people self-label, or not, presents challenges in reporting on such issues as terms are complicated to define. Despite such difficulties, individuals' freedom of expression is respected in using their own language.

There may be implications for individual clinicians, support staff, commissioners and those who design services, in how best to support people labelled with ID who are LGBT. It would be important to first collate and learn from existing research in working towards closing the policy-practice gap. Understanding the experiences of people labelled with ID as evidenced by qualitative research may be an important route to achieving this aim. The voices of people labelled with ID have historically been underrepresented in the research literature (Beail & Williams, 2014) yet directly asking service users about their views and experiences is recommended as good practice to ensure quality of services (DH, 2008). Without a focus on what people labelled with ID tell us about their LGBT sexualities and identities, new insights into improving current service provision and policy implementation might be missed. First-person narratives in qualitative research provide evidence of

psychological perspectives on lived experiences. Participants' accounts and researchers' interpretations can develop and expand upon new and existing psychological theories. These new understandings can influence people's lives indirectly through developing psychologically-informed services sensitive to the needs of LGBT people labelled with ID, and directly by individual clinicians gaining awareness of LGBT-specific wellbeing issues for people labelled with ID.

Historically, the sexuality of people labelled with ID has been associated with negativity and oppression. Legislation protecting equal human rights and policies aimed at improving services has gone only so far in improving their daily lives. The majority of existing research was conducted before legislative changes and findings were inconsistent. The current gaps in knowledge have clinical implications for those who provide support. A systematic review of qualitative literature is therefore needed to summarise psychological perspectives on non-heterosexual identities as experienced by people labelled with ID. Such a review has not previously been undertaken.

The aim of this review was to find, appraise and summarise primary qualitative research involving people labelled with ID who self-define as LGBT or are questioning a non-heterosexual identity. The focus was on the lived experiences of sexualities and identities recounted through their first-person narratives. An intended outcome was to inform future clinical and research recommendations.

[2]**Note on terms:** 'Intellectual disabilities' ('ID') is used throughout this paper as it is the internationally preferred term in research literature. The phrase 'people *labelled* with ID' is used to reflect the researcher's theoretical standpoint. 'Lesbian', 'gay', 'bisexual', and

'trans' ('LGBT') and 'non-heterosexual' were used interchangeably. See Appendix B for a more detailed note on terms.

## Method

A systematic review was conducted to establish:

"What do people labelled with ID who self-define as LGBT or are questioning a non-heterosexual identity say about their sexualities and identities?"

In this review, 'ID' was any ID label stated by researchers or participants where IQ scores were not reported, but did not include those whose IQ scores were listed as IQ>70 (a main classification criterion for ID is impaired intellectual function demonstrated by an IQ score two standard deviations below the general population mean: WHO, 1992). 'Self-defined as LGBT' and 'questioning a non-heterosexual identity' was stated by participants or reported by researchers and did not include participants with experience of past/current same-sex sexual behaviour or contact who self-defined as heterosexual at the time of their participation. Men labelled with ID who have sex with men might self-define as heterosexual despite regularly seeking same-sex sexual contact (Thompson, D., 1994). Terms are complicated to define and may occasionally seem contradictory. Consequently, such studies were not included in this review. The reviewer wanted to maintain a focus on the psychological perspectives of people who were at least questioning a non-heterosexual identity, rather than the potentially different perspectives of those with heterosexual identities. While this limits the scope of the review and is therefore a limitation, it was

anticipated that a broader inclusion would deviate too far from the review question and prevent meaningful conclusions being drawn. The conduct and reporting of this review was informed by Boland, Cherry, and Dickson (2014).

**Scoping Searches**

A scoping search (see Appendix C) was conducted in October 2013 to assess the availability of literature reporting the experiences of non-heterosexuality in people labelled with ID. Several studies were found, although more reported the views of family and support staff than the voices of individuals labelled with ID. Authors were contacted if their studies reported the first person accounts of non-heterosexual identities from people labelled with ID (see Appendix D for a list of authors contacted and a sample of correspondence). A list of retrieved studies was included in correspondence to authors. Additional references were cited by some responding authors and one advised on an expanded list of search terms to improve the review (see Appendix E). A search was conducted on PROSPERO (Centre for Reviews and Dissemination's international prospective register of systematic reviews) which found no comparable systematic reviews had been registered; no similar reviews were found via the Cochrane Database of Systematic Reviews (Wiley Online Library 1996 to current). It was concluded that the current review was both viable and necessary. A protocol was developed (see Appendix F) to guide the review process.

**Studies of Interest**

Inclusion and exclusion criteria were developed based on consideration of population, phenomenon of interest, and context (PICo; Joanna Briggs Institute, 2011; see Table 1.1), and are summarised in Table 1.2.

Studies with prison populations were excluded as total inability to access community resources, and legal restrictions on sexual choices, were expected to influence the psychological perspectives of participants.

Studies without a primary focus on sexuality and identity (for example, HIV-focused) were excluded as the psychological impact of HIV and associated risk factors were not under review here. Such studies are worthy of reviews specific to psychological phenomena associated with their topic area and were beyond the scope of this review.

*Table 1.1*. PICo Table.

| **Population** | **Phenomenon of Interest** | **Context** |
|---|---|---|
| People labelled with ID who self-define as LGBT or are questioning a non-heterosexual identity (does not include those with a heterosexual identity who engage in same-sex sexual contact). | Thoughts, feelings, opinions, interpretations and descriptions of psychological phenomena connected to sexualities and identities and expressed through first person accounts of individuals in the population. | People living in a variety of community and hospital settings (but not prison contexts). |

*Table 1.2*. Inclusion and Exclusion Criteria.

| **Inclusion** | **Exclusion** |
|---|---|
| English language. | Non-English language. |
| Primary qualitative research. | Non-primary, quantitative, or non-qualitative research (e.g. literature review). |
| Peer-reviewed. | Non-peer reviewed. |
| People (any age and gender) labelled with ID. | People (any age and gender) without an ID label. |
| First-person accounts of people labelled with ID. | First person accounts of people without an ID label (e.g. family or professionals). |
| People who self-define as LGBT or are questioning a non-heterosexual identity. | People who do not self-define as LGBT or are not questioning a non-heterosexual identity (with or without same-sex experience). |
| Primary topic (defined by the objectives or aims of the research) of sexuality or identity. | Primary topic (defined by the objectives or aims of the research) not sexuality or identity (e.g. primary focus on HIV/AIDS) |
| Community and hospital samples. | Prison samples. |
| Data can be linked to participants (individual or group) who self-define as LGBT or are questioning a non-heterosexual identity. | Data cannot be linked to participants (individual or group) who self-define as LGBT or are questioning a non-heterosexual identity. |

**Identification of Studies**

Studies were identified by searching electronic databases (see Table 1.3). These databases were considered the most relevant to clinical psychology and the social sciences. Specific social care databases were not included as these tended to list multimedia citations rather than the primary qualitative research relevant to this review. Search terms included: "intellectual disability", "lesbian", "gay", "bisexual", "transgender", and "qualitative", with variations and related words (for a full list of search terms see Appendix G). Additional studies were identified by searching the reference lists of retrieved articles which met inclusion criteria. References lists of subsequently included articles were searched and the process repeated until no new studies were identified.

*Table 1.3*. List of Databases Searched.

| Database | Platform and coverage (where known) |
|---|---|
| PsycINFO | EBSCO Host 1887 to current |
| Science Direct | Elsevier 1995 to current |
| Web of Knowledge | Thomson Reuters 1898 to current |
| Scopus | Elsevier 1823 to current |
| OpenGrey (System for Information on Grey Literature in Europe: SIGLE) | Exalead |

*Table 1.4*. List of Hand Searched Journals.

| Journal |
|---|
| British Journal of Learning Disabilities |
| Disability & Society |
| Journal of Applied Research in Intellectual Disabilities |
| Journal of Intellectual Disability Research |
| Journal of Intellectual & Developmental Disability |
| Journal of Policy and Practice in Intellectual Disabilities |
| Sexuality and Disability |
| Sexuality Research and Social Policy |

Key terms were entered into the search functions of several journal websites (hand searches; see Table 1.4) to identify studies which may not have been found via the databases. The publishing journals of studies included in the review at this stage were searched. These journals were considered the most relevant as they focused on ID and sexuality. To counter the effects of publication bias, unpublished research was included but only if it had undergone peer review (for example, PhD theses). Grey literature searches (to locate unpublished peer-reviewed research) and 'hand searches' were conducted to counter location bias. Limits to bias minimisation strategies are stated in the discussion. Electronic references were exported to and organised with the bibliographic software EndNote X7.

Duplicate citations were deleted using Endnote X7 and by hand. Searches were conducted in January 2014.

**Study Selection**

The reviewer screened all retrieved references. Relevance was assessed by applying inclusion and exclusion criteria (see Appendix H for a copy of the screening tool) to titles where they contained sufficient information, and to abstracts where titles were insufficiently detailed. References which could not be confidently excluded based on title and/or abstract remained included at this stage (stage one; see Figure 1). Full-text papers of all eligible references were then obtained electronically or in hard-copy and inclusion and exclusion criteria were applied (stage 2; see Figure 1).

**Data Analysis and Synthesis**

The reviewer's theoretical standpoint is largely interpretivist; and meta-synthesis approaches (for example, meta-ethnography; Noblit & Hare, 1988), which generate new understandings through interpretation of previously interpreted data, would have been preferred for this review. However, scoping searches suggested that sufficient data with which to answer the review question would likely be available but not extensive; and it was anticipated that there would be neither volume nor richness of data to employ an interpretative approach to data analysis and synthesis. While the volume of qualitative studies published in major ID journals has increased over the years, there are too few to systematically review some topics or to meta-synthesise data where these are available (Beail & Williams, 2014). Therefore, the reviewer adopted a 'narrative summary', the aim of

which was to summarise currently available evidence relevant to the review question. Narrative summary facilitated the inclusion of data from studies which utilised a range of methodologies, which might have been less appropriate had the reviewer sought to generate higher-order transformations of data as in, for example, meta-synthesis. The choice of synthesis was based on Dixon-Woods et al. (2005). See Appendix I for a table listing several approaches to data synthesis and the reviewer's conclusions on their appropriateness for this review.

**Quality Assessment**

The Critical Appraisal Skills Programme's ten-question appraisal tool (Qualitative Research Checklist; CASP, 2013) was used by the reviewer to inform a quality assessment of all included studies. Question ten on the tool was changed from 'how valuable is the research' to 'how relevant is the research to this review question'. Table 1.5 summarises the quality assessment (see Appendix J for one completed record from the quality assessment). All studies remained included after quality assessment as the function of the appraisal was not to further inform inclusion/exclusion in this review, rather, to aid the reader's understanding of how conclusions were drawn in this paper. The reviewer felt it would be inappropriate to assign numerical ratings to the overall quality of each study due to the heterogeneity of methodologies and the limitations of assessing the quality of qualitative studies (see Discussion). The reviewer rated each study on all 10 CASP tool questions. Ratings were: high (++) where adequate information was provided to fully answer the question, medium (+) where information was provided but additional detail would have

more adequately addressed the question, and low (-) where information was not provided or where it suggested a negative response.

**Data extraction**

Narrative summary requires summation of study characteristics and data relevant to the phenomena of interest (Joanna Briggs Institute, 2011). Extracted data from studies in this review therefore included, but were not limited to: author, title, aims, research question(s), sample description, inclusion/exclusion criteria, data collection methods, data analysis, presented themes, and conclusions. Data were extracted for each study using a data extraction tool (see Appendix K). Table 1.6 summarises key data. In studies with non-heterosexually-identified samples, all stated themes and conclusions were extracted. In studies with mixed-sexuality samples where individual participants' sexualities were stated, themes were extracted which linked to non-heterosexual participants as evidenced by their direct quotes; conclusions were extracted if they linked directly to extracted themes. Several extracted themes and conclusions were informed by both heterosexual and non-heterosexual participants (in samples where participants' sexualities were not individually stated) to avoid excluding data from non-heterosexual participants. The limitations of mixed samples are stated in the discussion.

*Table 1.5.* Summary of Quality Assessment Using CASP Tool.

| | | | Papers assessed (1st author, year) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Abbott (2005) | Bennett (2007). | Davidson-Paine (1995). | Stoffelen (2013). | Thompson, S.A. (2002). | Withers (1997). | Appleby (1994). | Elderton (2011). | Withers (2001). | McClelland (2012). | Yacoub (2008) | Rushbrooke (2014). |
| **CASP tool questions summary** | 1 | Clarity of research aims? | ++ | ++ | + | ++ | ++ | ++ | ++ | + | ++ | ++ | ++ | ++ |
| | 2 | Qualitative methodology appropriate? | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ | ++ |
| | 3 | Appropriate research design for research aims? | ++ | + | + | + | ++ | ++ | + | + | + | + | ++ | + |
| | 4 | Appropriate recruitment strategy for research aims? | ++ | + | + | + | ++ | ++ | + | + | ++ | + | + | + |
| | 5 | Appropriate data collection for the research issue? | ++ | + | + | + | ++ | ++ | + | + | + | + | + | ++ |
| | 6 | Consideration of relationship between the researcher and participants? | - | - | - | - | ++ | ++ | ++ | - | + | - | - | - |
| | 7 | Consideration of ethical issues? | ++ | + | - | ++ | ++ | ++ | + | + | ++ | + | + | ++ |
| | 8 | Was the data analysis sufficiently rigorous? | ++ | + | - | + | ++ | ++ | + | + | + | ++ | ++ | ++ |
| | 9 | Clarity of findings? | ++ | ++ | - | ++ | ++ | ++ | ++ | + | ++ | ++ | ++ | ++ |
| | 10 | Relevance to this review question? | ++ | ++ | ++ | ++ | ++ | ++ | + | + | + | + | + | + |

**Key**: ++ high quality, + medium quality, - low quality.

*Table 1.6*. Key Characteristics of Included Studies.

| 1st Author and year | Aims/objectives | Country and setting | Data collection | Data analysis | Interviews per participant | Interview / focus group length | Sample size | Age range | Gender identities[1] | Sexual identities[2] | Disability labels[3] | Living contexts |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Main focus on LGBT identities** | | | | | | | | | | | | |
| Abbott (2005). | Find out about the lives of LGB people labelled with ID; what helped / hindered people in expressing their sexualities, meeting other LGB people and forming relationships if desired. | UK (all four countries); mixed. | Interview. | Grounded theory. | 1 | 1-3.5 hours. | 20 | 22-59 | F (9), M (11). | B, G, L. | ID. | NK |
| Bennett (2007). | Explore how gay men labelled with ID perceive their statuses as both gay and men with ID, institutional and societal responses to them, and any effects on wellbeing. | UK (London); urban. | Interview. | IPA. | 1 (assumed). | 1-2 hours. | 10 | 27-54 | M (10). | G, Q. | ID. | Care home (6), with family (2), independent (2). |
| Davidson-Paine (1995). | Focus on feelings and perceptions of sexuality, issues and problems for young gay men labelled with ID. | UK (London); urban. | Interview. | Thematic*. | At least 2 (no totals stated). | NK. | 2 | NK | M (2). | G (2). | ID. | Independent (2). |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Stoffelen (2013). | Gain insight into the lifestyle of a cohort of people labelled with an ID who are homosexually active or who identify as gay or lesbian, what are their positive and negative experiences, and support needs. | Netherlands; NK. | Interview. | Thematic*. | 1 | NK. | 21 | 20-62 | F (2), M (19). | G (19), L (2). | ID. | NK. |
| Thompson, S.A. (2002). | Investigate how gay or bisexual men labelled with ID manage their complex identities, how do they come to identify as gay/bisexual, what does identity mean to them, how do they participate in LGB communities. | Canada and USA; mixed. | Interview. | Thematic*. | 1-3 | 1-4.75 hours. | 7 | Late 20s to mid 40s | M (7). | B (1), FI (2), G (4). | ID. | NK. |
| Withers (1997). | Explore how men labelled with ID who have sex with men incorporate their sexual behaviour and disabilities into their identities, how do they strive to achieve psychological wellbeing despite two potentially stigmatising aspects | UK; NK. | Interview. | Grounded theory. | 3-5 | NK. | 4 | 29-46 | M (4). | B (1), FI (2), ND (2). | ID. | Independent (1), with parents (1), supported house (1), other with support (1). |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | of themselves. | | | | | | | | | | | |
| Appleby (1994). | Explore the intersection of disabled and lesbian identities; question the accessibility of lesbian community for disabled lesbians. | UK; mixed. | Interview. | Thematic*. | 1-several (no totals stated). | 2 hours-several months (but no totals stated). | 9 | NK | F (9). | L (9). | Physical (8), ID (1). | Various, but not explicitly stated. |
| **Main focus on service evaluation** | | | | | | | | | | | | |
| Elderton (2011). | Service evaluation of a support group for LGBT people labelled with ID, focus on group identity and future direction. | UK (Oxford); mixed. | Interview. | Thematic. | 1 | NK. | 17 | 21-69 | F (5), M (11) T (1). | B,L,G. | ID. | NK. |
| Withers (2001). | Evaluation of a support group for men labelled with ID who have sex with men, focus on improved psychological wellbeing related to sexual identity. | UK (North West England); NK. | Focus group. | Content analysis. | 1 | NK. | 5 | NK. | M (5). | B, G, ND. | ID. | NK. |
| **Main focus on sexual health outcomes** | | | | | | | | | | | | |
| McClelland (2012). | Explore how social and environmental conditions influence vulnerability to adverse sexual health | Canada (Toronto); urban. | Interview and focus group. | Thematic*. | 1 interview, 1 focus group. | NK. | 10 | 17-26 | F (2), M (4), T (4). | B (1), Fl (3), G (2), L (3), Q (1). | ID. | Various, independent (4). |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | outcomes for LGBT youth labelled with ID. | | | | | | | | | | | |
| **Main focus on sexual knowledge and experiences (mixed LGBT and non-LGBT sample)** | | | | | | | | | | | | |
| Yacoub (2008). | Explore sexual knowledge, experiences and attitudes of men labelled with ID in community and secure hospital settings. | UK (London); urban. | Interview. | Iterative approach. | 1 (assumed). | NK. | 17 | 19-65 | M (17). | G (4), ND (3), S (10). | ID. | Community (10), secure hospital (7). |
| **Main focus on intimate relationships (mixed LGBT and non-LGBT sample)** | | | | | | | | | | | | |
| Rushbrooke (2014). | To contribute to and expand current evidence base in the area of intimate relationships for people labelled with ID. | UK (North West England); mixed. | Interview. | IPA. | 1 (assumed). | 27-55 minutes. | 9 | 21-58 | F (4), M (5). | B (1), G (1), ND (2), S (4), Q (1). | ID. | Supported house (5), with parents (2), independent (2). |

**Key:**

[1] F=Female, M=Male, T=Trans, fluid and gender queer. (Totals listed if known.)

[2] B=Bisexual, Fl=Fluid identities, G=Gay, L=Lesbian, ND=Not defined, S=Straight, Q=Questioning. (Totals listed if known.)

[3] ID=Exclusively those with Intellectual Disabilities but may have additional disability labels, Physical=Physical disability labels but not including ID. (Totals listed if known.)

* Thematic analysis assumed if not otherwise stated by the author.

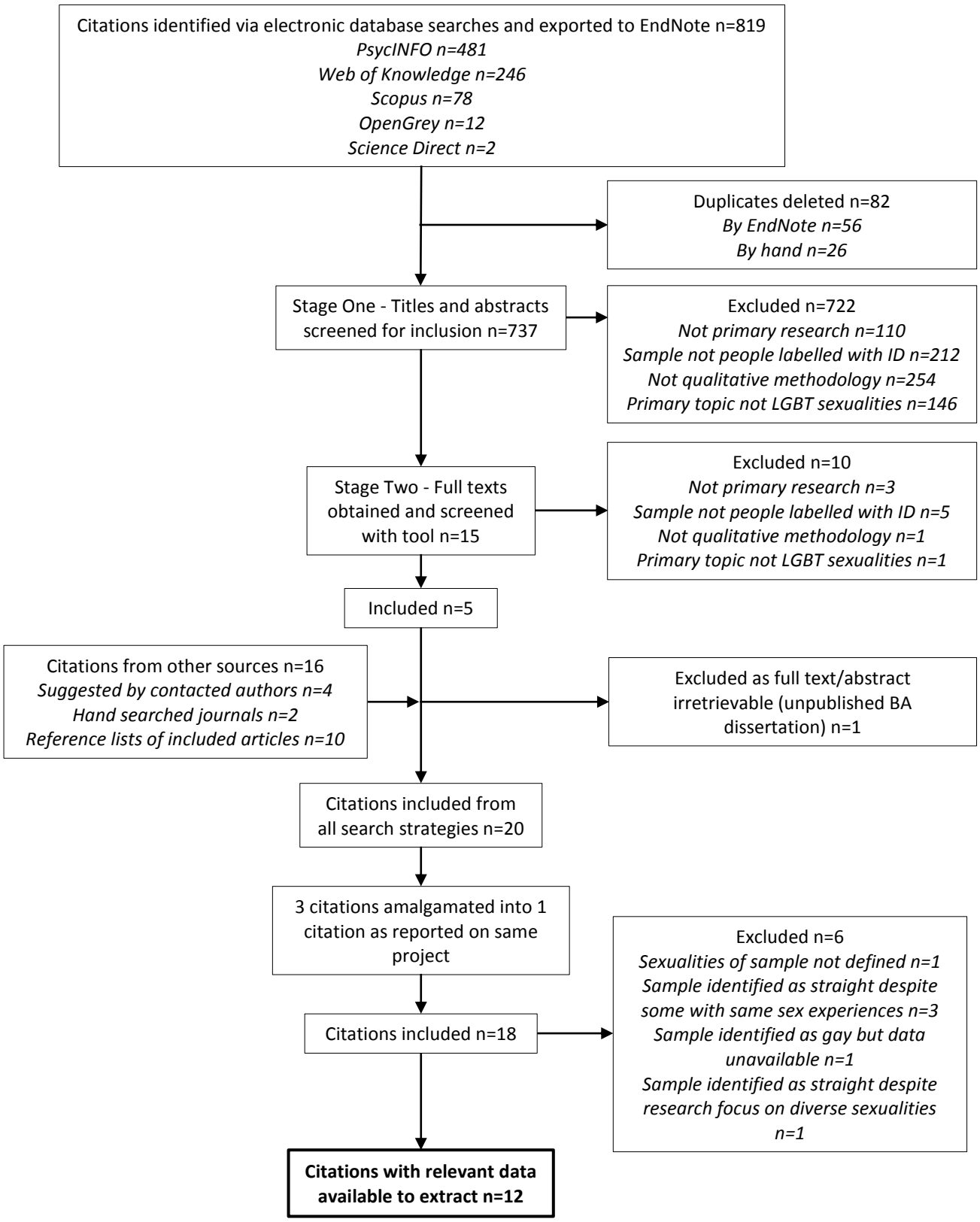
NK=Not known.

IPA=Interpretative Phenomenological Analysis.

ID=Intellectual disability.

LGB=lesbian, gay, and bisexual.

*Figure 1.* Flowchart of Search Strategy.



## Results

A search of electronic databases found 819 citations. Duplicates were deleted; and following screening at stages one and two, five citations remained. Citations from reference lists of included studies, those suggested by contacted authors, and from hand searching journals, added a further 16 citations. One reference was excluded as it was an unpublished and irretrievable BA dissertation. Of the 20 remaining citations, three (Abbott & Howarth, 2005; Abbott & Burns, 2007; Abbott, 2013) reported data from the same study (Abbott & Howarth, 2005) and were amalgamated into one data set (Abbot et al., 2005). Six of the remaining 18 citations were excluded as data were unsuitable to answer the review question. For example, Thompson, D. (1994) reported on the sexual experiences of men with ID who have sex with men; however, none of the participants identified as other than heterosexual. Thompson, D. (2001) reported on the mixed sexual experiences of men labelled with ID; however, sexual identities were not defined. A total of 12 studies were included in the review. Informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (PRISMA; Liberati et al., 2009), Figure 1 outlines the search, retrieval and inclusion processes.

The quality assessment of included studies is summarised in Table 1.5. Data relevant to the review question were extracted for each study using a data extraction tool (see Appendix K) which included research aims and context, design and methods, sample characteristics, themes and conclusions.

Sample sizes varied from two to 21, with an overall total of 107 potentially LGBT-identified participants. Male participants represented an overwhelming majority with a male to female ratio of approximately 4:1. Five participants identified as trans and participated in only two studies. Most data were collected via interviews ranging in total

duration per participant from 27 minutes to 4.75 hours. Six studies specifically aimed to investigate LGBT sexual identities in samples of people labelled with ID (one study included only one participant labelled with ID, the rest of the sample had physical disabilities); two studies reported on evaluations of specific services for LGBT people with ID; the remaining three investigated sexual health outcomes, sexual knowledge and experiences, and intimate relationships. Key themes and findings are discussed below. Key characteristics of each study are summarised in Table 1.6, where they have been grouped by their main research focus.

**LGBT Identities**

People labelled with ID had formed a variety of sexual identities. Gay, lesbian, and bisexual labels were often adopted (Abbott et al., 2005; Davidson-Paine & Corbett, 1995; Stoffelen et al., 2013; Appleby, 1994). Not all participants who reported having had consensual same-sex sexual experiences had formed LGBT identities. In several instances, participants appeared to be questioning their sexual identities and were exploring the possibility of a gay identity yet did not self-label as gay (Bennett & Coyle, 2007; Rushbrooke et al., 2014). Several had fluid identities often influenced by context and which fluctuated between various labels (Thompson, S.A., 2002; Withers, 1997). One participant rejected all sexuality labels and another fluctuated between gay and straight labels yet neither felt comfortable as he struggled to accept sexuality as part of himself (Withers, 1997). Yacoub and Hall (2008) found that half of those who had same-sex experiences identified as gay. One person who identified as gay had no sexual contact with his male partner, who he lived with, or anyone else. Some participants' labelling of their sexual identities were inconsistent

during their interviews and authors concluded this was likely to be a result of not knowing the meanings of the words ‘gay’ and ‘straight’ (Yacoub & Hall, 2008).

Identity awareness and comfort with self-expression changed over time with some experiencing fear and embarrassment in connection with their sexual expression (Rushbrooke et al., 2014). Those who had experienced acceptance of their sexualities from their social groups or who had lived with openly gay caregivers had formed largely positive gay identities (Thompson, S.A., 2002). One bisexual person felt a sense of identity pride and advocated for the rights of gay and bisexual people (Withers, 1997). Others’ identities were characterised less by pride and more by guilt and distress with little acknowledgement of their rights to a sexual existence (Withers, 1997).

**Coming Out**

Those who identified as LGBT had often been aware of their non-heterosexual feelings from a young age (Abbott et al., 2005; Bennet & Coyle, 2007; Davidson-Paine & Corbett, 1995; Rushbrooke et al., 2014; Stoffelen et al., 2013). All had ‘come out’ (disclosed their sexuality) to at least one other person and most had mixed positive and negative reactions from the various significant people to whom they had come out. All had carefully considered to whom they disclosed their identities. Bennett and Coyle (2007) reported that people were more likely to have come out to support staff but most had also come out to family and friends. Prior fear of rejection was prominent despite most having experienced largely positive responses and a subsequent sense of relief. Nearly all participants had someone they did not wish to come out to (Bennett et al., 2007), including to their support staff (Appleby, 1994). Stoffelen et al. (2013) found that around half of those who came out to

family members received positive reactions, though parents generally did not want to discuss sexuality. Some experienced very negative reactions to their disclosures, including rejection (Davidson-Paine & Corbett, 1995) and loss of contact (Stoffelen et al., 2013). Family members' negative reactions to participants' gay identities caused distress (Yacoub & Hall, 2008). People commonly did not come out in all contexts. Some only came out within LGBT social networks, believing that non-LGBT identified people were likely to be hostile towards them (Withers, 1997).

**Bullying and Harassment**

Almost all participants spoke of bullying and harassment in connection to their sexualities. Many experienced verbal and physical abuse from strangers in public (Abbott et al., 2005; Stoffelen et al., 2013), verbal abuse from close family members, and explicit and indirect homophobia from staff (Abbott et al., 2005). Bennett and Coyle (2007) reported most had been discriminated against or endured some form of prejudice at some point in their lives as a result of being labelled with ID. They suggested that participants' awareness of negative attitudes towards ID heightened their sense of 'difference' from the mainstream and reinforced their minority status.

**Having an ID label in LGBT Contexts**

Being labelled as gay did not guarantee identity within LGBT communities (Thompson, S.A., 2002). Most people knew of gay pubs or other gay venues and wanted access to them (Bennett & Coyle, 2007). Many had been to gay social venues and while some enjoyed it, some felt excluded, experienced barriers to access, or did not enjoy it (Abbott et al., 2005;

Bennett & Coyle, 2007; Davidson-Paine & Corbett, 1995). People felt it was important to be part of a gay social context but many needed support to access this (Bennett & Coyle, 2007). Despite several barriers, some were able to establish positive gay identities (Davidson-Paine & Corbett, 1995).

Some people said that they 'dropped' their ID label in gay contexts as they experienced issues connected with being LGBT and labelled with an ID (Abbott et al., 2005). Some resented being labelled with ID in LGBT contexts and even though they fitted in with the disabled community they desired validation from LGBT communities (Thompson, S.A., 2002). One person's account conveyed the message that adopting a gay identity emancipated him from an ID label (Thompson, S.A., 2002); and some regarded ID as negative aspects of themselves (Withers, 1997). There were, however, elements of fluidity and contextual influences reported in most studies.

**Social Contact with Other LGBT People**

Stories of social isolation and loneliness featured in most studies; and it was clear that people desired a sense of belonging to LGBT communities. Amount of contact varied between participants and studies. Some reported little meaningful LGBT social contact and especially limited opportunities to meet other LGBT people with ID (Bennett & Coyle, 2007). Others found an even split between those with limited LGBT contacts and those with several (Abbott et al., 2005). Social contact with other LGBT people engendered a sense of feeling at ease with one's self and others (Elderton & Jones, 2011). Generally, men were more likely than women to know other LGBT people (Abbott et al., 2005; Elderton & Jones, 2011). Lesbians and trans people felt they lacked social contact with other lesbians and trans

people (Elderton & Jones, 2011). Attendance at a support group for men labelled with ID who had sex with men facilitated participants to acknowledge their sexual differences and discuss more positive aspects of gay and bisexual identities (Withers et al., 2001). After attending the group, participants no longer considered their unique sexual identities as inferior.

**Supported Living**

Participants wanted support staff to help them to meet other LGBT people (Abbott et al., 2005), yet satisfaction with the support people received varied. Some felt unsupported with their sexuality (Appleby, 1994), while others who had access to gay and lesbian staff felt it facilitated positive discussion of LGBT issues (Stoffelen et al., 2013). Some experienced care as restricting their ability to live openly as LGBT people (Bennett & Coyle, 2007); and some staff declined to discuss sexuality even when participants had questions (Stoffelen, et al., 2013). Those who had or sought same-sex partners often hid their sexualities from others, attempting to protect themselves from others' negative reactions or protect others from upset (Rushbrooke et al., 2014). Sanctioned living environments influenced the sexual expression of participants' LGBT identities and resulted in more sexually risky experiences (McClelland et al., 2012). Often more than one other person was perceived to have authority and influence over participants' opportunities for sexual expression (McClelland et al., 2012).

### Desire for Relationships

Stoffelen et al. (2013) reported that approximately half of those interviewed were in long-term relationships, with the other half seeking partners. Abbott et al. (2005) found only a few people had current relationships but most had experience of being in a relationship at some point; and some did not focus on monogamous relationships. Rushbrooke et al. (2014) found that intimate relationships were valued and desired.

### Sexual Abuse and Identity

Incidents of abuse were common. In two studies (Abbott et al., 2005; Stoffelen et al., 2013) half of those interviewed reported having been sexually abused at some point in their lives. Another suggested the majority of the sample had experienced abuse (Bennett & Coyle, 2007). Some participants linked the abuse experiences with their sexual identity development (Abbott et al., 2005; Bennett & Coyle, 2007).

## Discussion

A total of 12 primary qualitative research papers were included in this review. A range of bibliographic databases of published and unpublished research relevant to clinical psychology and the social sciences were searched using a thorough, but not exhaustive, string of key terms. Scoping searches suggested data would be limited, however, supplementary hand searches of reference lists and journals, and papers that were suggested by authors published in the field revealed a larger dataset. The reviewer was

confident, therefore, that conclusions drawn in this systematic review were based on considerations of all relevant available research.

The review question aimed to summarise first-person narratives of people labelled with ID who were LGBT or questioning a non-heterosexual identity. What the review revealed was often contradictory and complex and offered only an introduction to some key issues in this under-researched area. Contradictions were found in how people self-identified, with some individuals fluctuating between gay and straight labels, some preferring not to use any labels to name their attractions and behaviour, and others identifying as LGBT. People who identified as LGBT had come out but most were not out to everyone. Coming out was anxiety provoking and participants often received a mixture of positive and negative responses. Positive responses reduced distress while negative responses added to distress. Some people rejected ID labels when in LGBT contexts to avoid expected hostility, while others did not but wanted staff to support them to access LGBT social environments. Some participants knew few other LGBT people despite wanting LGBT social contacts, while others knew several LGBT people. Many care environments were experienced as restricting participants' ability to live openly as LGBT people with staff who were unsupportive of their sexuality, while others felt supported and some had positive experiences with LGBT staff who openly discussed sexuality. Most people had experienced bullying and harassment related to ID or sexuality. Many had also been sexually abused and some linked the abuse to their sexuality development. Many participants wished to have partners and although they often had experience of relationships most were not currently in intimate relationships.

There were variations in what participants said about their sexualities and identities. Fixed and fluid self-labelling varied, as did sexual experiences, expression, and self-

disclosure. There were commonalities and differences within and between participant samples. Despite ID and LGBT labels potentially equating to two interacting and stigmatized identities, some people labelled with ID formed positive LGBT identities while others did not. The reviewer found no similar previously published systematic reviews with which to compare the findings. Previous research had tended to focus on staff views; and where LGBT people labelled with ID had been included in research, the emphasis had largely been on reducing adverse sexual health outcomes.

The overall assessed methodological quality of the included studies was generally considered to be medium to high, with one study in the low range. Variation in sample characteristics and research contexts across studies determined relevance to this review. There was diversity in the research focus of included studies; more significance was given to findings from studies which explored LGBT identities as a primary aim. In studies with mixed LGBT and heterosexual participant samples, some data were attributable to LGBT participants while authors' conclusions were often not LGBT-specific. Data analysis was most often thematic with some using grounded theory and IPA methodologies. Few reported the researcher having adequately considered their own theoretical standpoint or the relationship between themselves and the participants. Potential bias in data analysis was underreported.

**Strengths**

A comprehensive search strategy was developed from an initial literature review, pilot searches, consultation with research supervisors (clinical psychologists specialising in working with people labelled with ID) and several authors who had previously published

research in the area of LGBT sexualities in people labelled with ID. Search terms included the most relevant key words and phrases from an almost limitless number of idiosyncratic descriptors. Inclusion criteria were necessarily broad to identify potentially relevant studies in an under-researched area. The overall search strategy was therefore inclusive. A key strength of the review was its unique focus on first-person narratives of LGBT people labelled with ID. The systematic review process was favoured over a narrative literature review due to its reproducibility, transparency and the confidence subsequently attributed to its conclusions. All studies were quality assessed by the reviewer using a published appraisal tool. Including only peer-reviewed research added to the quality assurance. Narrative data summary highlighted the diversity of people's experiences, it allowed studies with different methodologies to be included, and avoided over-interpreting the limited data available. Discrepancies and gaps in knowledge were revealed without compromising the methodological rigor of the review. More in-depth data syntheses may only be appropriate with an expanded and richer evidence base from which to draw. This review suggests this is currently unavailable.

**Limitations**

Despite an extensive search strategy there are several parameters that may have influenced which studies were included in this review. The reader is encouraged to consider these limitations when extrapolating from the presented data and conclusions.

Qualitative study titles are often comprised of participant quotes and while guidance is available on reporting standards for qualitative research, methods are not universal. Potentially, some relevant qualitative papers were not identified via database searches.

Non-English language papers were excluded and relevant data might therefore not have been included. Screening of references and full text articles, quality assessment, and data extraction was independently undertaken by the reviewer. Cross-checking a sample of references with another reviewer or having a second reviewer perform the tasks simultaneously could have added credibility to the process. Some identified papers included the phrase 'men who have sex with men', although this was not included in the review search terms (omitted in error). It is therefore possible that some other potentially relevant papers were not retrieved.

Previous research suggested inconsistent findings about whether or not people labelled with ID who engage in same-sex sexual behaviour link their behaviour with a sexual identity. Some studies provided data from people who had experience of same-sex sexual contact yet these were not included as participants self-labelled as heterosexual or their self-labels were not reported. Prison populations were excluded as sexuality expression might differ in community and prison contexts. Excluding such studies was an attempt to remove confounding variables which might have led to past inconsistencies in the literature. As results showed heterogeneity in sexual experiences and identity labels, however, it is possible that important perspectives were not represented in this review. Living context was assumed to be 'community' unless otherwise stated in reported studies, which is a potential limitation of the screening process.

Limitations of quality assessing qualitative studies are not unique to this review. General guidance is available and appraisal tools offer a framework with which to approach the task; tools share similarities but all offer differences. As quality assessment relies on subjective interpretation it is open to non-transparent bias. Explicit reporting of the process may increase reproducibility but is impractical and uncommon. As quality appraisal was

based on reported information alone, the assessment may reflect the standard of reporting rather than the quality of the research per se. The validity and utility of the process can therefore be questioned. However, use of a standard tool was intended to provide increased transparency and reproducibility, and studies were not excluded on the basis of their assessed quality.

**Applicability of Findings**

People have highly idiosyncratic journeys in their sexual identity development and it is not possible to define typical LGBT sexual identity or provide a definitive and generalizable summary of 'what people say' about themselves based on the available data. Methodological limitations and heterogeneity across studies could have influenced the findings presented in this review. Women and trans people were underrepresented and caution should be taken in applying the findings to these groups. The historical, social, and political contexts in which the studies were conducted would likely have influenced participants' experiences and the researchers' approach to the data analysis and overall research processes. Studies spanned three decades (the earliest reported in 1994 the latest in 2014), in which time social, political, and legal climates have continuously evolved. ID- and LGBT-identified people in the UK are afforded more legal protections now than ever before and people may have access to more positive LGBT role models in popular culture. There were too few studies in this review, however, to identify any effects of such changes. Three studies were conducted outside of the UK; cultural context might be an important factor. It is conceivable that these could be significant influences in identity development. Those studies with a primary focus on LGBT identities which included people with fluid or

undefined sexual identities tended to be the earlier reported studies. It is possible that any positive effects of social and legal change had yet to have been experienced by those participants.

**Clinical Implications**

The implications of this review extend to clinical psychologists and other clinicians/therapists, support staff, and service managers. Clinical psychologists might implement these recommendations directly with service users through individual or group interventions, consultation and training with other clinicians and support staff, in planning psychologically-informed services, or working with service managers to update existing care pathways.

Service users cite issues with relationships and sexual lives as reasons for presenting to services (Yacoub & Hall, 2008). As this review found that service users might hold relatively fixed or fluid sexual identities and label their attractions and behaviour in numerous ways, it would be important to be cautious about making assumptions based on labels or behaviour alone. Psychologists might therefore need to hold sexuality issues in mind for all service users and question the meaning of the words individuals use to describe or define their identities, to develop accurate and shared understandings.

Individual therapy for those who think they are LGBT or are questioning a non-heterosexual identity might involve exploring whether coming out might ease their distress or if not coming out is functional in some circumstances, and should be included in related formulations. Individuals should be helped to think about who might be safe to come out to. If service users are not already out to their carers due to anticipating rejection,

consultation and/or joint working with carers may be appropriate to support individuals to come out if they wish to do so.

Psychologists should expect that bullying and sexual abuse are likely to be relevant for many service users who identify as non-heterosexual. Such issues may need to be addressed in therapy or support groups may be appropriate where these are available.

Positive responses to coming out relieve distress yet some receive negative reactions from family and staff. Support staff may therefore require training to understand the positive psychological consequences of being proactive in discussing sexual and identity issues with their clients. Service users may lack LGBT social contacts and may benefit from being supported to access LGBT support groups. As LGBT staff are often not out to service users, staff might require training to increase confidence in this area. Service providers should encourage and support LGBT staff to act as positive role models through appropriate self-disclosure. Services should recognise that absence of appropriate support for sexuality needs in the presence of avoidable psychological distress could constitute a breach of human rights. Sexuality issues may therefore need to be routinely supported by all staff within teams and all teams who support service users.

**Research Implications**

This review has confirmed that few recent studies have been conducted which ask people labelled with ID about their non-heterosexual identities. Most existing studies were conducted prior to the introduction of important legislative protections for LGBT people in the UK, or were conducted outside of the UK. Therefore, much remains unknown of how LGBT people labelled with ID experience their sexual identities in the UK in the current

socio-political climate. This review confirms the need for more qualitative research to expand the evidence base in this area and to develop further insights into the subtle complexities of non-heterosexual identities.

This review demonstrates that some people labelled with ID are willing and able to take part in research exploring the deeply personal issues of sexuality and identity. Although several studies have explored sexuality and have included LGBT participants, few have focused on the perspectives of LGBT people labelled with ID. The voices of LGBT labelled with ID are scarce in the research literature and further qualitative research would increase the visibility of this somewhat 'hidden' population. This review excluded samples who identified as heterosexual or were not questioning a non-heterosexual identity, despite same-sex sexual contact. Future research should focus on these groups to explore how they perceive their identities and to compare findings with the current review. Only then could meaningful conclusions be realistically developed regarding what people labelled with ID say about their non-heterosexual identities.

**Conclusion**

A systematic review was conducted to address the question: "what do people with intellectual disabilities who self-define as LGBT or are questioning a non-heterosexual identity say about their sexualities and identities?" A narrative summary of findings was presented and discussed in relation to quality appraisal of included studies, and strengths and limitations of the review process. People labelled with ID described their LGBT identities, sexualities and experiences in a variety of ways, some complementary, others contradictory. Some participants identified as LGBT while others fluctuated between

various labels and some preferred not to label at all. Most participants had mixed positive and negative responses to their coming out. Many people had experienced bullying, harassment and abuse, which they associated with their sexualities. This systematic review highlighted that there are significant gaps in knowledge about the lives and experiences of people labelled with ID who are LGBT. Social, political and legal climates have evolved in the UK over the last three decades in which the studies were conducted and some studies took place outside of the UK. It is conceivable that these factors might have resulted in some of the variation in participants' responses but this has yet to be established. The findings of this review should be considered in light of its limitations. Supporting individuals with their sexual identity formation and expression has implications for clinical practice. More qualitative research is needed to focus on this area to expand the evidence base and form more meaningful conclusions from data synthesis.

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## Chapter 2: Empirical Paper[3]

# 'Them Two Things Are What Collide Together':

# Understanding the Sexual Identity Experiences of Lesbian, Gay, Bisexual and/or Trans People Labelled with Intellectual Disability

[3]Article prepared for submission to Journal of Applied Research in Intellectual Disabilities for peer review. Please see Appendix A for author guidelines. Please note that these guidelines differ from APA publication guidance. Initials in in-text citations are given for authors Thompson, D., and Thompson, S.A., for clarity.

**Abstract**

*Background.* Previous research aiming to understand the lives of lesbian, gay bisexual and trans (LGBT) people labelled with intellectual disabilities (ID) is limited. There are few recent studies, and available findings are often contradictory and inconsistent.

*Method.* This study aimed to explore how LGBT people labelled with ID experienced their sexual identities. Five LGBT people labelled with ID were interviewed and data were analysed using IPA methodology.

*Results.* Four superordinate themes represented: common experiences of bullying/abuse, how participants understood their own and others' sexualities, how others responded to participants' ID and sexualities, and how they navigated acceptance from others.

*Conclusions.* Strategies for coping with abuse maintained participants' engagement in local communities. Sexuality was often problematized by others despite being generally accepted by participants. Coming out was a continual process of decision making to facilitate safety and acceptance. Clinical and research implications are suggested.

*Keywords:* intellectual disability, non-heterosexual sexuality, identity, coming out, interpretative phenomenological analysis

## Introduction

Research exploring the lived experiences of people labelled with ID[4] who are lesbian, gay, bisexual and/or trans (LGBT) has been relatively scarce. Few recent studies have been conducted and previous findings have been inconsistent. Consequently, much remains unknown about how individuals experience their sexual identities. UK Government

strategies (Valuing People, DH, 2001; Valuing People Now, DH, 2009) highlighted sexuality as a key target area for improving support for people labelled with ID, yet progress has been slow and gaps exists between recommendations and the daily experiences of people labelled with ID (Joint Committee on Human Rights, 2008). There is a dearth of qualitative research involving individuals labelled with ID which makes only limited contributions to changes in policy and practice (Beail & Williams, 2014), and might account for some of these challenges.

One of the most extensive studies to have explored the lives of LGBT people labelled with ID (Abbott & Howarth, 2005) found that participants often held positive self-views about their sexualities, used LGBT labels to self-identify, and had 'come out' (disclosed their sexual identity) to at least one person, most likely to support staff but also to family and friends (Abbott & Howarth, 2005; Bennett & Coyle, 2007). LGBT staff, however, were not usually out to service users (Abbott & Howarth, 2005). Participants anxiously anticipated rejection prior to coming out even when responses were positive (Abbott & Howarth, 2005; Bennett & Coyle, 2007) and some participants concealed their sexualities to avoid expected negativity (Rushbrooke et al., 2014). Participants with access to LGBT staff were positive about being facilitated to discuss sexuality, while others found staff were reluctant to discuss it (Stoffelen et al., 2013). This might suggest that lack of available LGBT role models (Abbott & Howarth, 2005) is a factor in participants' coming out processes.

It is unclear how relevant mainstream models of coming out (for example, Cass, 1979) are to people labelled with ID, due to inconsistent findings of past research. Previous studies found some people struggled to label their identities (Withers, 1997), with some adopting heterosexual labels despite routine same-sex contact (Thompson, D., 1994). Others suggested identities were fluid, where self-labelling varied and was influenced by

contextual factors (Thompson, S.A., 2002; Withers, 1997). Experiencing acceptance of their sexualities from social groups facilitated positive gay identities (Thompson, S.A., 2002). Support group attendance for men labelled with ID who had sex with men facilitated participants to discuss positive aspects of their identities and reduced the emotional impact of personally held negative beliefs about their sexualities (Withers et al., 2001).

The current socio-political and clinical context is different from that in which these studies were conducted. LGBT people have more legal equality, for example, the Equality Act 2010, and the Marriage (Same Sex Couples) Act 2013. Although UK therapists have previously tried to help change the sexualities of LGBT clients (Bartlett et al., 2009), the British Psychological Society now advocates against harmful 'conversion therapies' (Shaw et al., 2012). As there is a lack of recent research it is largely unknown if any benefits of cultural, legislative and clinical changes have impacted the lives of people labelled with ID who are LGBT.

**Study Aims**

The main aim of this study was to explore: how do people labelled with ID who are, or think they might be, LGBT experience their sexual identities? Themes arising from the literature were also considered but not directly asked at interview: In what ways do participants perceive themselves as being involved in a process of coming out?; how do participants perceive any strengths and resilience in relation to their sexual identities, understand the influence of any role models in relation to their sexual identities, and make sense of any costs and/or benefits of decisions to come out?

[4]**Note on terms:** 'Intellectual disabilities' ('ID') is used throughout this paper as it is the internationally preferred term in research literature. The phrase 'people *labelled* with ID' is used to reflect the researcher's theoretical standpoint. 'Lesbian', 'gay', 'bisexual', and 'trans' ('LGBT') and 'non-heterosexual' were used interchangeably. See Appendix B for a more detailed note on terms and Appendix L for the researcher's epistemological position.

## Method

### Design

This qualitative study facilitated an interpretative exploration of experiences of minority sexualities in a sample of adults labelled with ID, via individual semi-structured interviews. Data were analysed using interpretative phenomenological analysis (IPA; Smith, 1996; Smith & Osborn, 2008; Smith et al., 2009).

### Rationale

IPA privileges individuals' unique perspectives without seeking objectivity (Smith & Osborn, 2008), which accords with the researcher's epistemological stance (see Appendix L). IPA is suited to data from small and homogenous samples which enables detailed exploration of psychological phenomena (Smith et al., 2009). Grounded theory, thematic and narrative analyses were considered less appropriate to the current research aims (see Appendix M for further details of the rationale for IPA methodology).

**Participant Characteristics**

Pseudonyms were given to maintain anonymity. Ages ranged from 18 to 47. Participants were three males, one trans person and one female. One person identified as 'bisexual', the others as 'gay' or 'lesbian' (participants' labels). All participants lived in the community: some lived alone, others lived with parents. Table 2.1 summarises participant demographics.

*Table 2.1*. Participant Demographics.

| Participant pseudonym[+] | Gender* | Sexuality* | Attends ID-LGBT group? | Attends generic LGBT group/service? | Length of interview |
|---|---|---|---|---|---|
| David | male | gay | yes | yes | 65 min |
| Anthony | male | gay | yes | yes | 54 min |
| Jennifer | trans | bisexual | no | yes | 31 min |
| Kenneth | male | gay | yes | no | 66 min |
| Alice | female | lesbian | yes | yes | 41 min |

**Procedure**

**Ethics.** NHS ethical approval (see Appendix N) was granted prior to participant recruitment and data collection.

**Recruitment.** Participants were recruited from an LGBT-specific NHS service in a city in the north of England. The service did not have in-house psychological provision. Service access was via self-referral/professional referral and attendance was voluntary. The service ran a staff-facilitated support group for LGBT people labelled with ID (ID-LGBT group) and generic LGBT groups. The ID-LGBT group met fortnightly for two hours in the service base.

Its focus was informal health and social support with open-ended drop-in access. See Table 2.2 for inclusion/exclusion criteria for participation eligibility. The research questions in this study had not previously been discussed within the group. No assessment of intellectual functioning or sexual orientation took place; ID and sexuality labels were discerned from participant self-disclosure (see Appendix L for further details on the researcher's epistemological stance). Potential participants were identified and approached by the ID-LGBT group facilitators with whom they were familiar. Facilitators made attendees aware of the research by reading aloud the Participant Information Sheet (PIS; see Appendix O). Those who were interested were offered individual meetings with the researcher. One person did not attend the ID-LGBT group but met inclusion criteria; she was approached by staff and offered a meeting with the researcher.

*Table 2.2*. Inclusion/Exclusion Criteria for Participation.

| **Inclusion** | **Exclusion** |
|---|---|
| Attendance at LGBT service and/or ID-LGBT group. | Non-attendance at LGBT service. |
| Disclosure of ID label by individual. | Non-disclosure of ID label by individual. |
| Disclosure of LGBT label/questioning a non-heterosexual identity. | Non-disclosure of LGBT label/not questioning a non-heterosexual identity. |
| 18 years of age or older. No upper age limit. | Younger than 18 years of age. No upper age limit. |

***Informed consent.*** An accessible PIS and consent form (see Appendix P) were developed based on Department of Health and National Research Ethics Service guidance (DH, 2010; NRES, 2011) with advice from research supervisors (clinical psychologists specialising in working with people labelled with ID) and Mencap to ensure potential participants were provided with enough information to make informed choices to

participate. The term "learning difficulties" was used on the PIS and consent form as this was the term used by the IG-LGBT group. Seven potential participants were approached by staff. Six met with the researcher to find out more. The researcher read through the PIS, answered any questions and explained what would happen if they chose to take part. The researcher demonstrated audio-recording equipment and showed a copy of a journal when explaining intended dissemination of findings. Those who wished to take part returned on a different day to sign a consent form prior to interview. After two meetings with the researcher and discussions with support staff, one person decided not to participate, stating concerns regarding confidentiality and anonymity. This demonstrated the value and utility of the informed consent process in this study. Five people participated in total (four of the six regular attendees of the ID-LGBT group and one person labelled with ID who attended generic LGBT groups).

**Interviews.** Interviews were audio-recorded and transcribed. Participants were interviewed once individually (nobody chose to have a support worker with them) at the LGBT service base as this was a safe, confidential and familiar space. Participants were reminded that participation was voluntary and that they could withdraw from the study at any time. An interview schedule (see Appendix Q) was developed from a literature review and consultation with research supervisors to ensure congruence with IPA. To facilitate an idiosyncratic account congruent with IPA, the researcher avoided directly asking the research questions. Questions were generally open ended and explored: self-labelling; awareness of sexuality; self-disclosure; perceptions of others; and engaging with support services.

**Participant wellbeing.** LGBT service support staff were available to participants at all times during the research. The researcher had a list of local services to offer participants

psychological and other wellbeing support if needed following interview. Interviews ended with questions about wellbeing and immediate support needs. No participants needed support beyond their current provision.

**Reflexivity.** Researchers' personal contexts influence research processes (Smith & Osborn, 2008) and reflexivity makes their understandings explicit (Stevenson & Cooper, 1997). Personal details and prior expectations are given to contextualise the data analysis. The researcher was an able-bodied, 31 year-old, White British, out gay male, in full-time employment and studying for a Doctorate in Clinical Psychology. The researcher lived, worked, and grew up in the city where the research took place. The research interest developed following reflections on epistemological stance, personal experience of sexual identity development and navigating a coming out process, and being aware of lack of service provision in supporting people labelled with ID in relationships. The researcher expected that all participants would self-identify as LGBT (as the sample was recruited from an LGBT service), participants would have come out to at least one person and would experience similar feelings about coming out as people without an ID label, yet daily social restrictions would have significant negative psychological impact. The researcher kept a reflective diary (see Appendix R for an excerpt) to enable expectations, personal views and emerging ideas to be reflected on during data analysis.

**Data analysis.** There is no single method of data analysis in IPA (Smith et al., 2009). Data analysis was informed by Smith and Osborn (2008) and Smith et al. (2009). Transcripts were read multiple times, initially while listening to interview audio-recordings. Transcripts were line-numbered with wide margins on the left and right with the original text in a central column. The right margin was used to note descriptive, linguistic, and conceptual features within the text (see Appendix S for a sample). Emergent themes were noted in the

left margin in later readings and were based on the researcher's annotations. Emergent themes were transferred to separate documents with participant identifiers and line numbers linking them to the data (see Appendix T for a sample). Similar themes were grouped and renamed to refine the list. Related themes were clustered and cluster labels were further grouped into superordinate themes. A table of themes with related quotes was produced for each participant (see Appendix U for a sample). The process was repeated for each transcript separately (case-by-case analysis) before themes tables were considered together (cross-case analysis) for convergences and divergences within the dataset to produce a master list of themes.

**Feedback to participants.** A summary of key recommendations from the research was provided in an accessible format to all participants.

**Quality Assurance.** Quality assurance guidance for qualitative research (Elliott et al., 1999) informed the conduct of this research. Table 2.3 shows how quality was demonstrated in the current research. See Appendix V for details of the 'audit trail' (Yin, 1989).

*Table 2.3*. Quality Assurance Demonstrated in the Current Research.

| **Quality assurance process** | **Demonstrated in the current research** |
|---|---|
| Owning one's perspective[1] | Reflexive account given of the researcher's position in the research. |
| Situating the sample[1] | Participant demographics and contextual information provided regarding recruitment. |
| Grounding in examples[1, 2] | Themes were evidenced by quotes from all participants[1] with a minimum of three participants represented in each theme[2]. |
| Credibility checks[1] | Theme development discussed and clarified with research supervisors. |
| Participant validation[1, 3] | Specific follow-up questions were asked during interviews where clarification of participants' accounts was necessary[1]. Participant validation of analysed accounts was not sought[3]: IPA's double hermeneutic means that data analysis is the researcher's interpretation of how the participant made sense of their experience. |
| Audit trail[4] | Results can be traced back to original data via themes tables and annotated transcripts. |

[1]Elliot et al. (1999); [2]Smith (2011); [3]Smith et al. (2009); [4]Yin (1989)

## Results

Data analysis resulted in four closely related themes: living with abuse and discrimination; knowing sexuality; experience of ID and LGBT; and navigating acceptance from others. Themes are evidenced by pseudo-anonymised quotes. Participants' emphasis is shown in *italics*; text in brackets [] was added by the author for clarity. Table 2.4 lists all themes and the representation of participants within each.

**'People Throw Coffee In My Face': Living With Abuse and Discrimination**

Analysis suggested all participants experienced abuse and discrimination to varying degrees. Some regularly experienced insults from local community members which they linked to their sexuality ('it was homophobic bullying': Anthony), gender expression ('people don't like the way I look': Jennifer), or disabilities ('I used to get called "mong"': Kenneth). Participants encountered threats of violence ('I've been threatened with guns [and] knives': David) and actual physical assault ('people throw coffee in my face': Jennifer). While abuse occurred most frequently in the community, some experienced bullying from family ('I've been called every name under the sun by members of my own family': David) and some from carers in their own homes ('if you dress as a woman we'll cut your clothes up with scissors': Jennifer). Participants experienced bullying at school and college ('they started calling me names': Alice) which they linked to their sexualities ('I always think the bullies had an idea that I was gay': Anthony). Alice was the only participant not to have experienced abuse outside of school or college.

Anthony named his experiences as abusive and wrong ('homophobic attacks', 'hate-crime', discrimination', 'abuse'), however, other participants did not. Participants generally had not reported abuse to the police. When Jennifer and Anthony asked for help they felt disregarded ('they fobbed me off': Anthony), unsupported ('the police told me to stay in my house and don't go out if I didn't like it': Jennifer) and disappointed ('I felt very let down by the police': Anthony).

Participants experienced a range of emotional responses. Anthony was 'panicky' in busy public areas after being attacked by 'yobs' and felt there was little support available ('there was nowhere for me to talk about my feelings and the upset'). David conveyed a

sense of emotional disintegration and disorientation: 'I've had my life smashed into thousands of pieces and I've had my life turned upside down like you wouldn't believe. But what can I do'. David's feelings were so extreme that he could not imagine that they could be understood by others without personal experience ('like you wouldn't believe'). Other participants tended to minimise the emotional impact of their experiences. Jennifer stated how she was 'not bothered' and 'didn't care'. Her attempt to seek police assistance, however, suggested that she would prefer not to have experienced such incidents. Kenneth prioritised physical harm over emotional pain and although he named both as 'hurt', he implied that only threats to physical safety would be acted upon:

> 'it doesn't bother me really but sometimes it does, you know, when you're feeling down … that's when it does hurt, but you've just got to get on with it. Until they start hurting me, that's when I'll do something'.

Initially, participants seemed to convey a sense of feeling stuck with their experiences ('but what can I do': David). Kenneth, however, implied that he was resigned to verbal abuse ('that's life … that's what you get') and that he dealt with it alone ('you've just got to get on with it'). His comments highlighted stoicism in other participants, who also appeared to tolerate threats of extreme violence with little or no support ('they threaten to bomb my house and rape me, stuff like that': Jennifer), which characterised their emotional responses and approaches to coping. All had developed unique coping strategies for dealing with difficult experiences which included: verbal defence ('I shout at them': Jennifer), seeking support ('I will go to the police': Anthony), not listening ('turn my hearing aids off':

Kenneth), and cognitive avoidance ('I have to suppress it and I have to cloak it as if there's nothing there': David). Kenneth felt 'lucky' that he could report abuse if needed ('at least we don't live in Russia where they hunt gays down and hurt them') and conveyed a sense of feeling protected by his family's reputation ('everyone knows my family … so they are not going to hurt me when I've got my family there'). Resilience was a key feature in participants' accounts which enabled them to maintain their usual activities despite experiencing abuse and discrimination.

### 'It's In Your Genes': Knowing Sexuality

Analysis suggested that participants had ideas about their own and others' sexuality development and expression.

**'You know what you are': Understanding sexuality.** Participants felt that sexuality was innate and became aware of their sexualities during childhood: 'it starts in school, you *know* because it's in your genes, you *know* what you are' (David). Non-heterosexuality was experienced as personally conventional ('it's natural for me to be with blokes': Anthony), freely accepted and defined by attractions ('I knew that I wasn't attracted to any boy, I *just* didn't like them in that way': Alice). Sexuality was accepted as unremarkable and normal, as revealed by a linguistic focus on participants' use of the word 'just'. Participants explained how sexuality develops ('they just grow up like that': Jennifer) and how people become aware of sexuality ('it's just like when a straight person doesn't decide they're straight, they are *just* straight and they know that': Anthony). 'Just' featured in all participants' accounts and conveyed a sense of an intuitive and unquestioning understanding of sexuality and its development.

*Table 2.4*. Table of Themes and Representation of Participants Within Themes.

| **Theme** | **Participants** | | | | | |
|---|---|---|---|---|---|---|
| | **David** | **Anthony** | **Jennifer** | **Kenneth** | **Alice** | **Theme present in over half the sample?** |
| Living with abuse and discrimination | + | + | + | + | + | + |
| Knowing sexuality | + | + | + | + | + | + |
| *Understanding sexuality* | + | + | + | + | + | + |
| *Reading sexuality in others* | + | - | - | + | + | + |
| *Self-acceptance* | + | + | + | + | + | + |
| Experience of ID and LGBT | + | + | - | + | + | + |
| *Others problematizing ID and sexuality* | + | + | - | + | + | + |
| *Sexuality integral to self* | + | + | + | + | + | + |
| Navigating acceptance from others | + | + | + | + | + | + |
| *Coming out and acting straight?* | + | - | - | + | + | + |
| *Importance of contact with similar others* | + | + | + | + | + | + |

**Key:** Superordinate theme; *Sub-theme.* Participant represented within theme: + / -

Most did not view sexuality as a choice ('that person hasn't chose to be gay': Anthony), however, Jennifer implied an element of choice in her gender transition: 'I just didn't want to live as a boy anymore so I live as a woman'. It was unclear, however, if she described a 'choice' to live as a woman or the choice to live openly as a woman. Kenneth married because he 'didn't want to be gay' which implied he believed that sexuality could be self-determined. His brief marriage ended in divorce after he began a relationship with a male friend: 'I was only married a month … it just didn't work out … so we sort of like split up'. Although his account initially seemed incongruent, the sense of inevitability of the relationship breakup due to his undeniable sexuality became apparent within the context of the significance of the word 'just'.

**'Gaydar': Reading sexuality in others.** Some participants felt they could discern others' sexualities instinctively ('you've got gaydar you just *know*': Kenneth), through being adept at understanding body language ('their actions … you know if a person is gay because I can read it': David), or by interpreting clothing choices ('because the way they dress': Alice). Anthony and Jennifer, however, did not share this view:

> 'even if someone's camp … it doesn't necessarily mean that they're gay … you don't know if someone's gay, no-one knows, unless they let you know' (Anthony).

Sexuality was generally embodied and how participants understood others' sexualities was important to how they expressed their own ('I'm not a boy, I'm just Alice … I don't care if I wear boys things I still look smart': Alice).

**'People have got the problem': Self-acceptance.** Most participants described a transitional process of self-acceptance. Most reported accepting their attractions when younger ('I always knew I was gay but I didn't know the name of it I just thought, oh yes, you fancy fellas … that's what it is': Kenneth) until they became aware of negativity associated with non-heterosexuality ('the only words I knew were faggot and stuff like that': Kenneth). Participants often internalised this negativity ('I thought there was something wrong with me': Anthony) before becoming more comfortable with themselves ('I just be myself now': Kenneth). Participants often located 'problems' within others and not themselves ('people have got the problem, you haven't got the problem': Jennifer), which seemed to enable them to form or maintain positive self-beliefs despite experiencing negativity from others ('they are jealous because I'm better than them and they can't be who they want to be so they take it out on me': Jennifer; 'I know I'm different but that's the way I want to be': Alice).

Some participants described discomfort with their sexualities at times. David attended Gay Pride marches which implied some pride in his gay identity. His pride was, however, enmeshed in experiences with which he remained in conflict and he described feeling abnormal: 'because of what I've got [HIV], because I have disabilities, because I'm gay, because I have mental health issues going on now and then'. David's statement, 'you know what you are', implied that he had internalised pathologising messages about non-heterosexuality, revealed by his use of the word 'what' rather than 'who'. David described struggling to cope with the burden of his situation (which included multiple bereavements):

> 'I'm a genuine, honest person, it's just that at the moment I'm going through like a nightmare but it'll pass, it'll pass probably, it'll pass'.

The nightmare metaphor suggested that the experiences felt so abnormal that David struggled to make sense of how they could be real. The suggestion that he was 'going through' the nightmare, and the self-soothing repetition of 'it'll pass', suggested that maintaining hope of future relief was a continual process, necessary to manage the potential for doubt implied with the word 'probably'. The juxtaposition of being 'genuine, honest' and experiencing a 'nightmare' symbolised David's conflict of uncertainty in whether bad things can happen to good people.

**'Them Two Things Are What Collide Together': Experience of ID and LGBT**

Participants described unique difficulties associated with sexuality and ID for which there were emotional consequences.

**'They think it's wrong': Others problematizing ID and sexuality.** Participants often experienced others as problematizing ID and/or their sexualities. People were often denied a sexuality as others believed them incapable of knowing their own minds: 'people have that view that people with learning difficulties can't make their mind up about sexuality … folk just say like it's a phase' (Anthony). Potential partners often rejected participants on the basis of moral judgements about their right to have relationships ('when you've got a disability they don't want to know you because they think it's wrong': Kenneth). Some participants experienced a sense of disgust from others regarding their sexualities ('they were like eeww, they always went like that': Jennifer) which had emotional consequences ('they make me feel like I am some kind of weirdo or something when I'm not': Anthony). The dehumanising effect of this was summarised by David:

> ‘people look at me as if I am some sort of a monster and I know I am not. I know I am not … It feels as if I actually come from another planet, it’s as if I don’t belong on earth anymore’.

The intensity of his dislocation was symbolised in his feeling like a creature from another world. David’s and Anthony’s counter, ‘I know I am not’, conveyed their struggle to convince others that they are normal human beings.

All except Jennifer named personal difficulties associated with ID. Anthony was the only participant to include ID when initially describing himself: ‘I’m fully out as a gay man [PAUSE] gay man with learning difficulties’. His hesitation, however, might have suggested an element of reluctance or conflict attached to the ID label. Alice’s experience of ID was characterised by a conflict between accepting ID as part of her normal life and valuing her resulting friendships, while simultaneously feeling abnormal and disconnected from family members and wanting to reject ID. Alice’s hesitations communicated her discomfort in holding these seemingly dissonant ideas:

> ‘Sometimes I get a bit angry having a learning disability because I can’t do things that normal people can do… I don’t want to have a disability … I just want to be like a normal, but, not normal, but, I don’t want to [have a disability], because all my family don’t have one, most of my friends do, so they’re like me, they understand.’

**'They don't want to support you with that bit': Sexuality integral to self.** Anthony, Kenneth and Alice were in contact with ID organisations as well as the LGBT support service. Services were experienced as offering partial support, catering for either ID or sexuality needs. Participants wanted inclusive support, however:

> 'people say they're there to support you but when you tell them I need support for this [gay sexuality] as well then they don't want to support you with that bit. When you explain that if you can't help me with that [gay sexuality] you can't help me with that either [ID] because them two things are what collide together' (Anthony).

Alice and Kenneth wanted to meet partners. Alice had been 'really upset' when her girlfriend left her ('she really hurt me … sometimes I don't want to come out the house, just want to stay in bed on some days'), and found that talking to staff at the LGBT service helped 'a bit'. Alice attended an ID organisation most days, she had disclosed her feelings to them, and felt they were supportive. Alice was the only gay person to use the ID service and often felt 'a bit out of it' when others talked about relationships. She anticipated further isolation at an upcoming speed-dating night arranged by the ID service: 'I don't think it's for lesbians so I'm going to be a bit out of it'. Kenneth experienced 'bad relationships' where partners had taken advantage of him because he was 'classed as gullible'. He described using alcohol to cope with difficult feelings: 'I felt that depressed I went out and had more than what I was supposed to and if I drink more than two pints I always end up in the hospital [due to a medical condition]'. Kenneth wanted a partner but feared being misled or hurt again. Kenneth and Alice both struggled with lack of opportunity to meet new partners

because of their sexualities. Alice felt that straight ID service users 'can just find someone easily, but I can't', and Kenneth's tone of voice expressed a sense of futility when he said of the LGBT service, 'you can't exactly come dating here'.

In isolation, the metaphor of a collision between Anthony's sexuality and ID support needs could be interpreted as representing his struggle to integrate these two aspects of himself. In the context of Alice's and Kenneth's experiences, however, Anthony's 'collision' is more likely to symbolise the impasse that he experienced in his requirement for unavailable holistic support. The collision's impact was felt emotionally: Alice's sense of disconnection, Kenneth's disappointment, and Anthony's dissonance. It seemed that neither service, separately nor combined, supported all the participants' needs. In contrast, Anthony felt that the LGBT service offered him 'the right support', however, he had not expressed a wish to find a partner.

### 'I Have To Watch What I Say': Navigating acceptance from others

Participants described how they experienced coming out in relation to acceptance from others.

**'I'd rather act straight': Coming out and acting straight?** David, Kenneth and Alice were not 'out' to everyone and their experiences revealed that coming out was more than a process of repeated self-disclosure. Deciding when it was appropriate to come out often resulted in participants not coming out. Some participants further concealed their sexualities by acting straight ('sometimes I act as if I am not even gay': David), which they felt skilled at ('some people think I'm straight because I'm straight acting': David). Acting

straight, however, was not always easy. Kenneth previously spoke in a deep voice to attempt to conceal his sexuality:

> 'I think I talk camp … so I have to watch what I say and think about it because I didn't want them to know … I used to have to drink a lot of water because my voice hurt that much … but now I just go "oh forget it" because it hurts, you know what I mean'.

Kenneth's use of present tense when speaking about past events ('I have to watch what I say') implied an on-going and effortful process of self-monitoring and censorship related to sexuality concealment/disclosure. Physical pain offered as a rationale for speaking in his normal voice suggested that Kenneth might have continued to alter his natural voice if it were easier to maintain. David described how it felt to 'act' straight and how often he adopted the role:

> 'When I am outside, when I am out, when I have to go somewhere someone else steps in my body, it just feels as if an alien steps in my body until I've done what I've got to do and then he comes out again and I go back to normal again … but then outside the alien takes over and sometimes I don't have no fear of nothing … people look at me as if I am intimidating, and I'm a jumped up scally lad wanting to fight all the time but I'm not 'cause people don't understand me, who I am'.

The straight role was symbolised by an alien who 'takes over'. This perceived lack of control illustrated its automatic and habitual presence. David experienced vulnerability and a sense of powerlessness in his gay identity and he preferred to act straight to reduce the sense of threat: 'I'd rather act straight, least that way I know where I am then'. The alien functioned to enable David to be fearless, however, it represented a conflict that David experienced in 'needing' to act unnaturally straight at the cost of being misunderstood. If Kenneth experienced a similar power differential it might have explained his inclination to physically strengthen his 'squeaky' voice.

Anthony and Jennifer were out to everyone and had not attempted to act the role of another sexuality or gender for self-protection or acceptance. Jennifer and Anthony, however, reported the highest incidence of abuse among the participants. Alice had not directly come out to the people with whom she spent most of her time: 'I haven't come out to them, but I think they know by the way I dress and that'. Alice described a tentative process where she simultaneously felt a sense of protection from rejection by not directly coming out, while maintaining her true sense of identity enacted through her clothing and appearance.

**'Someone that understands you': Importance of contact with similar others.** Contact with other LGBT people labelled with ID seemed important to participants. They valued spending time together ('I just come here so I can communicate with people': Jennifer), sharing activities and feeling understood ('just things that anyone would do but it's just nice to be with someone that understands you, not someone that doesn't': Anthony). Kenneth only felt comfortable in the ID-LGBT support group as he felt the generic LGBT group members were 'always bitching'. Meeting similar others reduced participants' sense of isolation ('most of my friends are straight apart from the people who come here': Alice).

Anthony described how meeting similar others was mutually beneficial: 'because I come here [ID-LGBT group] … I know that I can go out and support other people who are gay with learning difficulties'. As a result, Anthony felt empowered to act as a role model for others:

> 'because I am very loud and proud I think people feel comfortable around me that they can tell me stuff like that [homophobic abuse] because I've been there so they know it's better coming to me in a way because I am gay than going to someone else who's straight.'

## Discussion

This research aimed to explore the lived experiences of adults labelled with ID who identified as LGBT. An interpretative phenomenological analysis resulted in four superordinate themes which represented: common experiences of bullying and abuse, how participants understood their own and others' sexualities, how others responded to their ID and sexuality, and how they navigated acceptance from others.

Analysis suggested that participants experienced bullying related to ID, sexuality or gender expression while in their local communities, from family, friends and some staff. Incidents included verbal abuse, threats of violence and sometimes physical assault. Previous research found similarly high incidences of bullying or abuse related to ID (Bennett & Coyle, 2007) or sexuality (Abbott & Howarth, 2005; Stoffelen et al., 2013), and homophobic bullying was common for young people not labelled with ID (Guasp, 2012). In the current study, coping strategies including tolerating or switching off and Abbott and

Howarth (2005) found participants demonstrated similar stoicism. Disclosure of sexual abuse was expected (Abbott & Howarth, 2005; Stoffelen et al., 2013; Bennett & Coyle, 2007) but did not occur.

Participants labelled their identities 'lesbian', 'gay', 'bisexual' and 'trans'. This was consistent with some studies (Abbott & Howarth, 2005; Davidson-Paine & Corbett, 1995; Stoffelen et al., 2013), and contrasted with others which found some reluctance to use labels (Withers, 1997) or identify as gay/bi despite routine same-sex sexual contact (Thompson, D., 1994).

Participants described increased self-acceptance over time, similar to Cass (1979). Although participants had come out, most were not out to everyone. People commonly did not come out in all contexts when they anticipated LGBT-related hostility (Withers, 1997). Current participants who were out to everyone experienced the most frequent and violent abuse. Others described coming out as a continual decision-making process based on needing to feel accepted and safe. People not labelled with ID make similar safety-based decisions by assessing others' attitudes to non-heterosexuality (Lasser & Tharinger, 2003). Coming out was sometimes motivated by positive gain such as finding a partner or seeking support. Choosing not to come out was therefore functional and might have been the safest option in some circumstances.

Most participants did not mention ID when asked to describe themselves, despite most going on to name specific personal difficulties associated with ID. Past research suggested that some people avoided using ID labels in LGBT environments to reduce hostility (Abbott & Howarth, 2005; Thompson, S.A., 2002). One participant (Kenneth) routinely disclosed his ID label to potential partners in gay venues, usually resulting in rejection. Of all participants he described the most rejection of this type. Being out about

ID was similar to being out about LGBT identities as it often resulted in hostility. Deciding when it was appropriate and safe to disclose ID labels might have been useful for some participants. Not disclosing ID labels might therefore have been beneficial in some situations.

Participants defined their sexualities by their attractions and expressed them through actions, speech, and behaviour. Most felt that they had 'gaydar' or could 'read' sexuality in others and described 'knowing' sexuality as an intuitive rather than an intellectual process. As verbal communication difficulties are common for people labelled with ID (Iacono and Johnson, 2004), they may rely on non-verbal communication to express needs (Regnard et al., 2007) or read social cues from others (Lamb, 2012). Non-verbal communication was key to understanding others' sexualities and might have influenced when and with whom participants felt safe to come out. Clothing was important in how Jennifer and Alice expressed sexuality/gender. Extrapolating Butler's (1989) gender performance theory to sexual identity might suggest that participants could experience fluidity in sexuality expression (acting gay/coming out or acting straight/not coming out) without experiencing dissonance with their true identity, as identity exists only in its performance. Analysis suggested that participants who acted a straight role experienced negative emotional consequences, implying that participants had internalised sexual identities that were relatively stable, while their performance of sexuality was functional and context dependent.

Participants felt they had unmet needs as they often felt isolated and unsupported in ID services due to their LGBT identities, and felt LGBT services were ill-equipped to support people labelled with ID. Although people labelled with ID have increased rates of mental health difficulties (Whitaker & Read, 2006), Anthony described being gay with an ID label as

more challenging than being gay or having an ID label in isolation. Analysis suggested participants experienced unique challenges associated with ID and LGBT identities. Tentative evidence from participants suggested an intersectional perspective (Crenshaw, 1989), where all aspects of identity are considered to be inextricably linked, might be more useful in understanding participants' experiences than thinking about multiple discriminations as additive.

Participants valued social contact with LGBT people labelled with ID (similar to previous reports of ID-LGBT groups: Elderton & Jones, 2011; Withers et al., 2001). One participant (Anthony) described reciprocal support as he felt empowered to act as a role model for others because he was a member of the ID-LGBT group. As service users generally lack access to positive LGBT role models (Abbott & Howarth, 2005), this might be an important function of such a group.

**Strengths**

Analysis was based on rich data: participants often gave detailed accounts, including some striking metaphors, enabling an in-depth exploration of how they made sense of their experiences. The sample represented four of the six regular attendees of the ID-LGBT group. Analysis and conclusions represented a range of perspectives within this homogenous group. One person who expressed an interest in taking part in this research decided not to participate after careful consideration. This highlighted the robustness of the informed consent process and demonstrated that people labelled with ID can be facilitated to make informed choices about taking part in such research.

**Considerations**

Homogenous samples in IPA research mean that findings are not intended to represent whole populations. There may be important differences between the experiences of those who participated and those who did not. As recruitment was limited to one service, LGBT people labelled with ID who did not have access to this service might have had different experiences. Participants had access to openly LGBT-identified staff, which is uncommon (Abbott & Howarth, 2005) and may have influenced positive attitudes to their LGBT identities (Kenneth, for example, heard 'gay' more frequently spoken in a positive context at the LGBT service). Participants were likely to have at least partially adopted LGBT labels or understood them as relevant to themselves by virtue of attending the LGBT service. Participants had self-disclosed ID labels to the LGBT service to gain access to the ID-LGBT group, however, the researcher did not assess ID or seek further clarification of an ID diagnosis. Variation in IQ scores and social functioning were unexplored and, although unlikely, it was possible that some participants may not have met ICD-10 (WHO, 1992) diagnostic criteria for ID. Participants' subjective experiences and self-labelling were instead prioritised to maintain congruence with an IPA ethos. The research was limited in scope. Sexual abuse was not disclosed despite research suggesting abuse is common (Abbott & Howarth, 2005). As the researcher's motivation was not to lead participants' accounts, no direct questions were asked concerning sexual abuse. This does not mean it was irrelevant to participants. As with Kenneth's experience of coming out to his mother, indirect questions did not facilitate disclosure. The researcher would consider this in future. One trans person, one lesbian and one person living with HIV participated and these aspects of their experiences could not be adequately considered in this small-scale study. Quality assurance guidance (Elliot et al., 1999) informed the conduct of this research. Although

themes were evidenced by quotes from all participants during analysis, it was impractical to include the full range in this report, which might limit the reader's sense of participant's individual stories.

**Reflections**

As a gay man, the researcher had shared similar experiences to some participants. Benefits of 'insider' perspectives were considered in relation to the potential for bias. These were discussed in supervision and a reflective diary was kept to ensure the researcher was mindful of these influences during data analysis.

**Clinical Implications**

Recommendations may be implemented with service users through individual/group interventions, consultation and training with clinicians and support staff, planning psychologically-informed services, or working with service managers to develop/update care pathways. Suggestions are tentative and may warrant further exploration as they are based on findings from a sample of five. The results of data analysis were condensed in this report, for brevity. Implications for clinical practice are broader than the reported results as they originated from the unabridged data analysis.

Key recommendations:

- Be unambiguously affirmative about LGBT identities, asking direct questions to facilitate those who wish to come out. Stoic coping styles mean service users may be reluctant to seek help or admit to LGBT-related difficulties.

- Supporting service users to always be out may be unhelpful as it might increase vulnerability to abuse.
- Creating psychologically-informed care environments may give more opportunities to come out safely.
- Support service users to meet other LGBT people.
- Establishing links with third sector organisations may be crucial for LGBT community engagement.
- Expect bullying to be part of service user's stories (trauma-related stress is more common following homophobic hate-crimes than non-hate related crimes: Herek et al., 1999).
- Idiosyncratic coping strategies should be incorporated into formulations.
- Gay-affirmative therapy (Davies, 1996) might be useful.
- Facilitate service user training and support from police to recognise and report hate-crime and manage personal safety.
- Offer training to police to understand and respond appropriately to difficulties faced by people labelled with ID.
- Psychologists could link with police to provide support following homophobic attacks.
- Develop and widely disseminate co-produced (Boyle & Harris, 2009) resource packs for service users and staff about LGBT-related bullying.
- Augment story-based resources for LGBT service users (Howarth et al., 2005) with skills-based training to enhance service users' abilities to 'read' others and make safety-based decisions about coming out.

- Support service users to be involved in staff training or mentoring/role modelling for service users.

**Research Implications**

Suggestions are preliminary and may warrant further investigation to develop these ideas. In light of current findings, future research might investigate:

- Experiences of people without access to ID-LGBT groups.
- Navigating a continual coming out process and differences/similarities between those who are always out and those who are not.
- How strategies for responding to bullying vary.
- How enacted/performed sexuality might link with internal sense of identity (does identity remain relatively stable despite contextual changes in acting gay/straight).
- If people have a stable or fluid sense of identity.
- Experiences of trans people and lesbians labelled with ID. Previous researchers also made this recommendation (Abbott & Howarth, 2005) which might imply sampling issues have yet to be addressed.
- Identity experiences in people labelled with ID who have had same-sex experiences without developing non-heterosexual identities.

**Conclusion**

Five LGBT people labelled with ID provided rich data about their experiences of sexual identities. Data were analysed using IPA methodology. Analysis suggested that participants

developed strategies to cope with abuse and they continued to engage in local communities. Sexuality was often problematized by others despite being generally accepted by participants. Coming out was a continual process of decision making to facilitate safety and acceptance. LGBT people labelled with ID desired holistic service provision sensitive to their sexuality and ID needs to feel fully supported. Improving existing services through psychologically-informed practice and partnerships would be an efficient use of limited NHS resources. Sexuality was clearly important to participants' quality of life, yet this is an under researched area with many unanswered questions. It is important to continue to update the evidence base with new research to explore the issues highlighted in this study. This may help to address existing policy-practice gaps and move further towards improving human rights equality for people labelled with ID in practice, as well as in theory.

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**Appendices**

## Appendix A

### Journal of Applied Research in Intellectual Disabilities Author Guidelines

Relevant sections only of the guidelines are included here for brevity. The full guidelines are stored on the data record CD available upon request, or from:

http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%291468-3148/homepage/ForAuthors.html

**1. GENERAL** …The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision…

**5. MANUSCRIPT TYPES ACCEPTED**

***Original Articles, Review Articles, Brief Reports, Book Reviews*** and ***Letters to the Editor*** are accepted. ***Theoretical Papers*** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

**6.2 Structure**

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

***Cover Page:*** A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

***Running Title:*** A short title of not more than fifty characters, including spaces, should be provided.

***Keywords***: Up to six key words to aid indexing should also be provided.

***Main Text:*** All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

**6.3 References …** Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al*. 1977). Authors are responsible for the accuracy of their references.

## Appendix B

## Note on Terms

The terms 'learning disabilities' or 'learning difficulties' are commonly used in the UK in health and social care services. 'Intellectual disabilities' (ID) is used throughout this thesis as it is the internationally preferred term in research literature. The researcher was not completely comfortable using any of these terms; indeed, specific definitions and diagnostic classifications (for example, ICD-10; WHO, 1992) conflict to an extent with the researcher's theoretical standpoint. The researcher's opinion is that these are labels given to individuals usually by those in positions of relative authority, and that such labelling often renders its recipients to lower status and devalued positions in society. It is largely the 'othering' and devalued positions that creates problems for people given the label of ID than 'intrinsic' aspects of constituent ID criteria. This is similarly the case with terms relating to non-heterosexual sexual identities such as 'lesbian', 'gay', 'bisexual', and/or 'trans' ('LGBT'). LGBT and other associated labels, however, might be more often self-determined ('queer', for example) and therefore afford individuals relatively more power than a label of ID.

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## Appendix C

## Information on Scoping Search

A scoping search was conducted in October 2013 to establish if primary research data were available to systematically review. Table C1 lists the bibliographic databases searched and Table C2 lists search terms used.

Table C1. Databases searched.

| **Database** | **Platform and coverage (where known)** |
|---|---|
| PsychINFO | EBSCO Host 1887 to current |
| Science Direct | Elsevier 1995 to current |
| Web of Knowledge | Thomson Reuters 1898 to current |
| Scopus | Elsevier 1823 to current |

Table C2. Search terms

| | |
|---|---|
| **Intellectual disabilities** | (intellectual* OR learning OR development* OR mental*)<br>AND<br>(disab* OR impair* OR retard* OR handicap* OR defici* OR difficult* OR disorder)<br>AND |
| **Sexuality** | (lesbian* OR gay* OR homosexual)<br>AND |
| **Qualitative methods** | (semi-structured OR semistructured OR unstructured OR informal OR in-depth OR indepth OR face-to-face OR structured OR guide* OR interview* OR questionnaire* OR focus group* OR qualitative* OR ethnograph* OR fieldwork OR field work) |

Citations were imported to Endnote X7. Duplicates were deleted. Titles were screened for relevance based on inclusion/exclusion criteria listed in Table C3. Abstracts were read where titles were insufficiently detailed to aid screening.

Table C3. Inclusion and exclusion criteria.

| **Inclusion** | **Exclusion** |
|---|---|
| English language. | Non-English language. |
| Primary qualitative research. | Non-primary, quantitative, or non-qualitative research (e.g. literature review). |
| Primary topic (defined by the objectives or aims of the research) of sexuality or identity. | Primary topic (defined by the objectives or aims of the research) not sexuality or identity (e.g. primary focus on HIV/AIDS). |
| Primary topic (defined by the objectives or aims of the research) of people labelled with intellectual disabilities. | Primary topic (defined by the objectives or aims of the research) not people labelled with intellectual disabilities. |

The following full text articles were retrieved:

Abbott, D., & Burns, J. (2007). What's love got to do with it?: experiences of lesbian, gay, and bisexual people with intellectual disabilities in the United Kingdom and views of the staff who support them. *Sexuality Research and Social Policy: A Journal of the NSRC, 4*(1), 27-39.

Bennett, C., & Coyle, A. (2007). A minority within a minority: experiences of gay men with intellectual disabilities. In Victoria Clarke & Elizabeth Peel (Eds.), *Out in psychology: lesbian, gay, bisexual, trans and queer perspectives* (pp. 125-145). Chichester: Wiley.

Davidson-Paine, C., & Corbett, J. (1995). A double coming out: gay men with learning disabilities. *British Journal of Learning Disabilities, 23*(4), 147-151.

Löfgren-Mårtenson, L. (2012). "I want to do it right!" A pilot study of Swedish sex education and young people with intellectual disabilities. *Sexuality and Disability, 30*(2), 209-225.

McClelland, A., Flicker, S., Nepveux, D., Nixon, S., Vo, T., Wilson, C., . . . Proudfoot, D. (2012). Seeking safer sexual spaces: queer and trans young people labelled with Intellectual disabilities and the paradoxical risks of restriction. *Journal of Homosexuality, 59*(6), 808-819.

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It was concluded that primary research data were available and it would be feasible to develop a protocol for a systematic review.

## Appendix D

### List of Authors Contacted with Copy of Correspondence

**List of Authors Contacted by Email**
Professor Lotta Lofgren-Martenson
Dr Paul Withers
Mr David Abbott
Professor Jan Burns
Dr Sarah Flicker
Ms Joke Stoffelen
Dr Adrian Coyle
Dr Christopher Bennett

**Example of Email Correspondence**

Dear _____,

I am conducting a systematic review as part of my Doctorate in Clinical Psychology at the University of Liverpool. As you have previously conducted studies which are pertinent to my systematic review, I am emailing to enquire if you know of any other relevant primary research studies which might not have been published yet, or that I have not found despite my literature searches.

My research question is: "What do people with intellectual disabilities who are, or might be, lesbian, gay, bisexual, or transgendered say about their experiences of their sexualities / sexual identities?"

The studies which I have found as a result of my literature searches are:

(S*tudies retrieved from scoping search were listed but are not included here for brevity as these are a listed in Appendix C*)

Any further information you might be able to provide would be greatly appreciated.

Thank you very much for your time.

Best wishes,

Rob Dinwoodie
Trainee Clinical Psychologist

**Authors who responded suggested some additional references:**

Lotta Lofgren-Martenson:

- Löfgren-Mårtenson, L. (2009). The invisibility of young homosexual women and men with intellectual disabilities. *Sexuality and Disability, 27*(1), 21-26. doi: 10.1007/s11195-008-9101-0

Paul Withers:

- Elderton, A., & Jones, C. (2011). Finding a safe place to explore sexual identity. The monthly meetings of a group in oxford give its lesbian, gay, transgender and bisexual members a forum in which to be themselves. Anna Elderton and Chris Jones tell the story of Mingle. *Learning Disability Practice, 14*(5), 14-17.
- Fitzgerald, C., & Withers, P. (2011). 'I don't know what a proper woman means': what women with intellectual disabilities think about sex, sexuality and themselves. *British Journal of Learning Disabilities, 41*(1), 5-12.
- Withers, P. (1998). *When" clever" means" happy": disability, desire and distress.* Paper presented at the Clinical Psychology Forum.

David Abbott:

- Abbott, D. (2013). Nudge, nudge, wink, wink: love, sex and gay men with intellectual disabilities - a helping hand or a human right? *Journal of Intellectual Disability Research, 57*(11), 1079-1087. doi: 10.1111/j.1365-2788.2012.01642.x
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Jan Burns:

- Burns, J., & Davies, D. (2011). Same-sex relationships and women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*(4), 351-360. doi: 10.1111/j.1468-3148.2010.00609.x
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Joke Stoffelen

- Abbott, D. (2013). Nudge, nudge, wink, wink: love, sex and gay men with intellectual disabilities - a helping hand or a human right? *Journal of Intellectual Disability Research, 57*(11), 1079-1087. doi: 10.1111/j.1365-2788.2012.01642.x

## Appendix E

### Extra Search Terms Suggested by Contacted Author

Sarah Flicker forwarded the researcher's email to her co-author Zach Marshall, who suggested the following additional search terms:

**Additional Search Terms**

sexuality or sexual*

"men who have sex with men"

bisexual or trans*

**Search Term Not Included in this Review**

"Men who have sex with me" was omitted in error from the list of terms searched. This was named as a limitation of the review.

## Appendix F

## Systematic Review Protocol

**Title of Project**
What do people labelled with intellectual disabilities (ID) who self-define as lesbian, gay, bisexual, and/or trans (LGBT) or are questioning a non-heterosexual identity say about their sexualities and identities?

**Background and Rationale**
There has been relatively little research published about the sexualities of people labelled with ID. Assumptions of asexuality or heterosexuality have been made. Most existing research has focused on heterosexuality. Where LGBT sexualities have been explored, the focus has often been on negative associations such as HIV/AIDS risk factors or sexual knowledge in relation to right to have sex. Research has often focused on sexual behaviour and not the lived experiences of people labelled with ID who are LGBT. Research has often involved staff or carers and not people labelled with ID. Therefore little is known about what people labelled with ID think and feel about their LGBT sexualities. Their psychological needs are under researched. This could have clinical and research implications. A systematic review is needed to establish what prior research has taken place involving people labelled with ID who are, or think that they might be, LGBT, to collate what they have said about their sexualities and identities.

**Method**

**Study selection based on PICo:**

| | |
|---|---|
| *Population* | People labelled with ID who self-define as LGBT or are questioning a non-heterosexual identity. |
| *Phenomena of Interest* | Thoughts, feelings, opinions, interpretations and descriptions of psychological phenomena connected to sexualities and identities and expressed through first person accounts of individuals in the population. |
| *Context* | People living in a variety of community and hospital settings but not prison contexts. |

**Studies will be identified via searches of electronic databases:**
- PsycINFO
- Science Direct
- Web of Knowledge
- Scopus
- SIGLE.

**Search terms to be used:**
(intellectual* OR learning OR development* OR mental*)
AND
(disab* OR impair* OR retard* OR handicap* OR defici* OR difficult* OR disorder)

AND
(lesbian* OR gay* OR homosexual*)
AND
(semi-structured OR semistructured OR unstructured OR informal OR in-depth OR indepth OR face-to-face OR structured OR guide OR guides OR interview* OR questionnaire* OR focus group* OR qualitative OR ethnograph* OR fieldwork OR field work OR qualitative)

**Inclusion/exclusion criteria:**

| Inclusion | Exclusion |
|---|---|
| English language. | Non-English language. |
| Primary qualitative research. | Non-primary, quantitative, or non-qualitative research (e.g. literature review). |
| Primary topic (defined by the objectives or aims of the research) of sexuality or identity. | Primary topic (defined by the objectives or aims of the research) not sexuality or identity (e.g. primary focus on HIV/AIDS). |
| Primary topic (defined by the objectives or aims of the research) of people labelled with intellectual disabilities. | Primary topic (defined by the objectives or aims of the research) not people labelled with intellectual disabilities. |

**Searching other sources:**
Search the reference lists of included studies for relevant citations.
Hand search relevant journals for extra citations. Journals such as British Journal of Learning Disabilities, Journal of Intellectual Disability Research, and Journal of Applied Research in Intellectual Disabilities.

**Managing citations:**
Citations to be imported/inputted to EndNote X7. Duplicates to be deleted by EndNote X7 and by hand.

**Data extraction:**
Authors themes and conclusions to be extracted if evidenced by quotes from participants labelled with ID who are non-heterosexual. Other key data to be extracted for sample demographics and study description.

**Quality assessment:**
Use CASP quality appraisal tool for qualitative studies.

**Method of analysis/synthesis:**
Narrative summary. Likely to be limited data based on scoping search. Therefore interpretative syntheses not appropriate/possible.

## Appendix G

### Full List of Search Terms

| Full list of search terms | |
|---|---|
| **Intellectual disabilities** | (intellectual* OR learning OR development* OR mental*)<br>AND<br>(disab* OR impair* OR retard* OR handicap* OR defici* OR difficult* OR disorder)<br>AND |
| **Sexuality** | (lesbian* OR gay* OR homosexual* OR queer* OR bisexual* OR bi-sexual* OR "bi" OR "cross-sexual" OR "trans" OR trans-sexual OR transsexual* OR transgender* OR trans-gender* OR intersex* OR "third sex" OR androgynous OR hermaphrodite)<br>AND |
| **Qualitative methods** | (semi-structured OR semistructured OR unstructured OR informal OR in-depth OR indepth OR face-to-face OR structured OR guide* OR interview* OR questionnaire* OR focus group* OR qualitative* OR ethnograph* OR fieldwork OR field work) |

## Appendix H

## Copy of Screening Tool

### Example of an included study.

| | | |
|---|---|---|
| **Review question:** What do people labelled with intellectual disabilities who self-define as lesbian, gay, bi, and/or trans or are questioning a non-heterosexual identity say about their sexualities and identities? | | |
| **Inclusion criteria** (based on PICo and study design)<br>*Population* = Any age person labelled with an intellectual disability (ID) who self-defines as lesbian, gay, bi, and/or trans (LGBT) or is questioning a non-heterosexual identity;<br>*Phenomena of Interest* = first-person accounts + topic of sexuality/identity;<br>*Context* = Non-prison sample;<br>*Study design* = Qualitative. | | |
| **ID + LGBT + Sexuality/Identity Selection Tool** | | |
| **Reviewer name:** Rob Dinwoodie | | |
| **Date:** | | |
| **EndNote ID#:** #25114 | | |
| **Reference:** Stoffelen, J., Kok, G., Hospers, H., & Curfs, L. M. G. (2013). Homosexuality among people with a mild intellectual disability: An explorative study on the lived experiences of homosexual people in the Netherlands with a mild intellectual disability. *Journal of Intellectual Disability Research, 57*(3), 257-267. doi: 10.1111/j.1365-2788.2011.01532.x | | |
| | | |
| **Inclusion / exclusion criteria** | **All inclusion criteria met?** | **Notes** |
| **English language?** | Yes | |
| **Primary research?**<br><br>*Include:*<br>Primary studies.<br>*Exclude:*<br>Systematic review;<br>Meta-studies;<br>Literature review;<br>Books. | Yes | |
| **Qualitative methods?**<br><br>*Include:*<br>Interview;<br>Focus group;<br>Other qualitative method.<br>*Exclude:*<br>Quantitative; | Yes | |

| | | |
|---|---|---|
| Questionnaire only;<br>RCT;<br>Experiment. | | |
| **Primary topic LGBT sexuality?**<br><br>*Include:*<br>Aims/objectives explore LGBT sexuality.<br>*Exclude:*<br>Aims/objectives only explore heterosexuality;<br>No mention of LGBT. | Yes | What are the lived experiences of a specific cohort of homosexual people with an intellectual disability living in the Netherlands? |
| **Sample of people labelled with ID?**<br><br>*Include:*<br>Any age people labelled with ID.<br>*Exclude:*<br>People without ID label e.g. carers, staff;<br>No mention of ID. | Yes | |
| **First-person accounts of people labelled with ID?**<br><br>*Include:*<br>Reported on what people labelled with ID actually said.<br>*Exclude:*<br>No mention of what people labelled with ID said. | Yes | |
| **Community sample?**<br><br>*Include:*<br>Independent living;<br>Supported accommodation;<br>Assume community if no mention of living context.<br>*Exclude:*<br>Prison. | Yes | |
| **Peer-reviewed?**<br><br>*Include:*<br>Journal articles from peer-reviewed journals;<br>PhD theses (viva=peer review).<br>*Exclude:* | Yes | |

| | | |
|---|---|---|
| Non-peer reviewed research. | | |
| Overall decision | | Included |

**Example of an excluded study.**

| | | |
|---|---|---|
| **Review question:** What do people labelled with intellectual disabilities who self-define as lesbian, gay, bi, and/or trans or are questioning a non-heterosexual identity say about their sexualities and identities? | | |
| **Inclusion criteria** (based on PICo and study design)<br>*Population* = Any age person labelled with an intellectual disability (ID) who self-defines as lesbian, gay, bi, and/or trans (LGBT) or is questioning a non-heterosexual identity;<br>*Phenomena of Interest* = first-person accounts + topic of sexuality/identity;<br>*Context* = Non-prison sample;<br>*Study design* = Qualitative. | | |
| **ID + LGBT + Sexuality/Identity Selection Tool** | | |
| **Reviewer name:** Rob Dinwoodie | | |
| **Date:** | | |
| **EndNote ID#:** #24527 | | |
| **Reference:** Burns, J., & Davies, D. (2011). Same-Sex Relationships and Women with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*(4), 351-360. doi: 10.1111/j.1468-3148.2010.00609.x | | |
| | | |
| **Inclusion / exclusion criteria** | **All inclusion criteria met?** | **Notes** |
| **English language?** | Yes | |
| **Primary research?**<br><br>*Include:*<br>Primary studies.<br>*Exclude:*<br>Systematic review;<br>Meta-studies;<br>Literature review;<br>Books. | Yes | |
| **Qualitative methods?**<br><br>*Include:*<br>Interview;<br>Focus group;<br>Other qualitative method.<br>*Exclude:*<br>Quantitative;<br>Questionnaire only; | **No** | A cross sectional within group, correlational design using data from three self-report measures and demographical data. |

| | | |
|---|---|---|
| RCT;<br>Experiment. | | |
| **Primary topic LGBT sexuality?**<br><br>*Include:*<br>Aims/objectives explore LGBT sexuality.<br>*Exclude:*<br>Aims/objectives only explore heterosexuality;<br>No mention of LGBT. | Yes | Attitudes to same sex relationships. |
| **Sample of people labelled with ID?**<br><br>*Include:*<br>Any age people labelled with ID.<br>*Exclude:*<br>People without ID label e.g. carers, staff;<br>No mention of ID. | Yes | |
| **First-person accounts of people labelled with ID?**<br><br>*Include:*<br>Reported on what people labelled with ID actually said.<br>*Exclude:*<br>No mention of what people labelled with ID said. | **No** | Questionnaire data. |
| **Community sample?**<br><br>*Include:*<br>Independent living;<br>Supported accommodation;<br>Assume community if no mention of living context.<br>*Exclude:*<br>Prison. | Yes | |
| **Peer-reviewed?**<br><br>*Include:*<br>Journal articles from peer-reviewed journals;<br>PhD theses (viva=peer review).<br>*Exclude:* | Yes | |

| | | |
|---|---|---|
| Non-peer reviewed research. | | |
| Overall decision | | Excluded |

## Appendix I

## Rationale for Choice of Data Synthesis

This table has not been included here as it was an adaptation of copyrighted material for which the author did not have permission to publish.

The original table can be obtained from Dixon-Woods, Agarwal, Jones, Young, and Sutton (2005).

## Appendix J

## One Quality Assessment Record

### Example of a Quality Appraisal Record

**Author and year:** Abbott & Howarth (2005); Abbott & Burns (2007); Abbott (2013).

**Title of paper:** Secret loves, hidden lives? Exploring issues for people with learning difficulties who are gay, lesbian or bisexual.

| **1. Was there a clear statement of the aims of the research?** | **Yes X** | **Can't tell** | **No** |
|---|---|---|---|

Hint: consider

| | |
|---|---|
| • What was the goal of the research? | Aimed to uncover and understand more about the lives of LGB people with intellectual disabilities in the United Kingdom.<br>The focus of the research was to find out more about what helped and hindered these people in expressing their sexuality, meeting other LGB people, and, if desired, forming relationships.<br>Fill gaps in resources by producing accessible booklets about these concerns for LGB people with intellectual disabilities and the staff that support them.<br>Focuses primarily on what the 20 participating LGB men and women with intellectual disabilities had to say about relationships both current and past, as well as those relationships to which they aspired. |
| • Why is it thought important? | The voices of lesbian, gay, and bisexual people with intellectual disabilities have rarely been heard within both policy and research.<br>Research has long suggested that the sexual and relationship needs of people with intellectual disabilities have largely been overlooked.<br>The situation facing lesbian, gay, and bisexual (LGB) men and women with intellectual disabilities is arguably even more difficult than that of their heterosexual counterparts, given societal norms about sexuality in general and historical assumptions about the asexuality of people with intellectual disabilities in particular. |
| • Its relevance. | The United Kingdom is undergoing major policy reviews and changes in the way it organizes and delivers social care to people with intellectual disabilities.<br>Disabled people's rights to a (hetero)sexual identity and (hetero)sexual relationships have been recognized only relatively recently; still less progress has been made for people with intellectual disabilities who might identify as gay, lesbian, or bisexual. |

**Notes:**

| 2. Is a qualitative methodology appropriate? | Yes X | Can't tell | No |
|---|---|---|---|

Hint: consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants.

Sought to illuminate subjective experiences sought from under researched population.

- Is qualitative research the right methodology for addressing the research goal?

Appropriate method for research goals.

**Notes:**

| 3. Was the research design appropriate to address the aims of the research? | Yes X | Can't tell | No |
|---|---|---|---|

Hint: consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

Chose a semi-structured interview guide over an unstructured interview or survey questionnaire because wanted to capture people's views, opinions, attitudes, and experiences while allowing for some comparison between people in different types of services. A semi-structured topic guide provides an opportunity to collect complex qualitative data—allowing easier exploration of the interaction between beliefs, behaviour, and experiences—while following, in the main, standardized headings to allow for comparison.
The questions for the topic guides were developed after having carried out a literature review and identifying the main themes in previous, relevant research. Piloted the topic guides and consulted with two people with intellectual disabilities—one lesbian and one gay man—who acted as project consultants.

**Notes:**

| 4. Was the recruitment strategy appropriate to the aims of the research? | Yes X | Can't tell | No |
|---|---|---|---|

Hint: consider

- If the researcher has explained how the participants were selected.

Explanation of how services selected – participants recruited via services. Researcher recognised potentially biased sample of services – those who had already thought about or shown good practice in working with LGB people with ID. However, no definition of what constituted good practice or indeed bad practice, for the reader – how biased is biased.

- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by

Wanted a range of services from different parts of the UK and recruited through services, so assume wanted a range of participants from different areas – but not explicitly stated as such. But sample of people from England,

| | |
|---|---|
| the study. | Wales, Northern Ireland, Scotland.<br>Mentioned a selection criteria for services but did not state what it was. But did say wanted to include a range of services from various places. Good description of sample, but not mentioned where they came from e.g. rural, urban, which country – potential effect on access to gay scene etc. so difficulties might be similar to LGB without ID in that area??<br>Eligibility criteria for sample described well – clearly fitted with the aims of the research. Does not say if anyone was excluded or not. |
| • If there are any discussions around recruitment (e.g. why some people chose not to take part). | Not said how many services were contacted, and how many there were available. Are we supposing hardly any good practice or quite varied? Would have been good to know how many services out there, what proportion were contacted and how many were known to have good practice. Help to understand about which did not take part. |

**Notes:**
Considered appropriate to recruit via services as people might need support to access research – often people struggle to access media e.g. reading difficulties, many might not be able to initiate participation if not supported to do so.
Used range of recruitment options, from media, adverts, word of mouth, via staff. Thought to be appropriate given the nature of the research aims – difficult to find population.

| **5. Was the data collected in a way that address the research issue?** | **Yes X** | **Can't tell** | **No** |
|---|---|---|---|

Hint: consider

| | |
|---|---|
| • If the setting for data collection was justified. | Participants chose where to have interview and if male/female interviewer – rationale = to give as much choice as possible – but did not say explicitly why choice was important for the sample. Did not allow interview in bedrooms even though some participants requested this. |
| • If it is clear how data were collected (e.g. focus group, semi-structured interview etc.). | Semi-structured interviews. |
| • If the researcher has justified the methods chosen. | Justified fully why chosen semi-structured interview over unstructured interview or questionnaire. |
| • If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? | Topic guide main themes listed, account of its development – literature review, pilot and consultation with service users, one gay man, one lesbian, both with ID. |
| • If methods were modified during the study – if so, has the researcher explained how and why? | N/A. |
| • If the form of data is clear (e.g. tape recordings, video material, notes etc.). | Tape recordings, transcribed verbatim. |

| | |
|---|---|
| • If the researcher has discussed saturation of the data. | No mention of data saturation in description of analysis. Interviews between 1 and 3.5 hours long. No explanation as to why some much longer than others and if/how this affected the data analysis. |

**Notes:**

| **6. Has the relationship between the researcher and participants been adequately considered?** | **Yes** | **Can't tell** | **No X** |
|---|---|---|---|

Hint: consider

| | |
|---|---|
| • If the researcher critically examined their own role, potential bias and influence during | |
| • a) Formulation of the research questions. | No mention. |
| • b) Data collection, including sample recruitment and choice of location. | No mention. |
| • How the researcher responded to events during the study and whether they considered the implications of any changes in the research design. | No mention. |

**Notes:**

No account of the researchers was given – apart from to name that females were interviewed by the female researcher and males by the male. No background on either was given so the reader cannot think about how they might have influenced the research questions and analysis etc.

| **7. Have ethical issues been taken into consideration?** | **Yes X** | **Can't tell** | **No** |
|---|---|---|---|

Hint: consider

| | |
|---|---|
| • If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained. | Good account of informed consent process (video information with question and answer format with person with ID interviewing the researcher), contact with support worker with whom participant had pre-existing relationship. |
| • If the researcher has discussed issues raised by the study (e.g. issues around informed consent of confidentiality or how they have handled effects of the study on the participants during and after the study). | Potential support services available to participants if needed (and mentioned that one person was considering this option), right to not answer questions, confidentiality. |
| • If approval has been sought from the ethics committee. | Social services research ethics granted. |

**Notes:**

| **8. Was the data analysis sufficiently rigorous?** | **Yes X** | **Can't tell** | **No** |
|---|---|---|---|

Hint: consider

| | |
|---|---|
| • Is there is an in-depth description of the analysis process. | Explicit description of data analysis process – reading and rereading transcripts and field notes, identify major themes, comparison of themes for similarities and differences, grouping into broader categories, themes cross checked with the other researcher (credibility check) with attention to themes that appeared unusual or counterintuitive, further broad categories of themes developed. Transcripts then checked for accuracy and consistency in coding by each researcher. |
| • If thematic analysis is used – if so, how the categories/themes were derived from the data. | Reading and rereading transcripts and field notes, identify major themes, comparison of themes for similarities and differences, grouping into broader categories, themes cross checked with the other researcher. |
| • Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. | No mention. |
| • If sufficient data are presented to support the findings. | Quotes given for all points made. Quotes from a range of participants – but not all – not stated if anyone not included in the report (or why). Quotes clearly showed the ideas generated were based in the data. |
| • To what extent contradictory data were taken into account. | Themes cross checked with the other researcher (credibility check) with attention to themes that appeared unusual or counterintuitive. Good range of quotes – some showed similarities and differences between participants. |
| • Whether the researcher critically examined their own role, potential bias and influence during the analysis and section of the data for presentation. | The researchers did not state whether they considered their own roles in the data analysis and the impact they would have had – bias not discussed. |

**Notes:**
Appears sufficiently rigorous as clear steps to analysis described. Would have improved rigor by considering their own position to the participants and data – bias, and any gaps in data i.e. why some participants not quoted.

| **9. Is there a clear statement of findings?** | **Yes X** | **Can't tell** | **No** |
|---|---|---|---|

Hint: consider

| | |
|---|---|
| • If the findings are explicit. | Clear themes as headings. Researchers' interpretation given with quotes to illuminate points.<br>Good summary of main findings given in discussion section.<br>Results and quotes discussed in discussion section that did not appear on the results section – why? |
| • If there is adequate discussion for | Examples given of when individual participant's accounts |

| | |
|---|---|
| the evidence both for and against the researchers arguments. | differed from the majority of the sample. |
| • If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst). | Credibility – checked by the 2 researchers, theme development discussed and then original transcripts checked to see if they fitted with the data. |
| • If the findings are discussed in relation to the original research question. | Findings discussed in relation to other research and the main aims of the research were broad so broad discussion occurred. |

**Notes:**
No limitations of the study were discussed – but every study has them.

**10. How valuable is the research?**
**How relevant to this review? ++**

Hint: consider

| | |
|---|---|
| • If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice policy or relevant research-based literature? | The findings have implications for staff and service providers, as well as for social policies addressing disability, which do not routinely reference sexuality and personal relationships.<br>Findings discussed in relation to original research question, the wider current policies and existing literature and clinical practice/social care. |
| • If they identify new areas where research is necessary. | This study was part of a wider project, but did not state what other research would be helpful as a result of this study. |
| • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used. | Findings discussed in relation to disability research.<br>Suggestions made on changing organisations to facilitate staff to support LGB people to access gay community and potential intimate relationships. |

**Notes:**
Biggest sample of LGBT people with ID reported so far in any of the studies found.
Shows how people with ID can take part in research – justification for more access to future research.
Focus on relationships, identities, helps and hindrances to personal expression – positive (in contrast to much previous sexuality studies on negative aspects such as HIV, abuse, offending).

## Appendix K

## Data Extraction Tool

**Data Extraction Tool**

Data extraction records are stored on the data record CD, available upon request.

| **Review title**<br>What do people labelled with intellectual disabilities who self-define as lesbian, gay, bi, and/or trans or are questioning a non-heterosexual identity say about their sexualities and identities? | |
|---|---|
| **Publication details** | |
| Author | |
| Year | |
| Title of paper | |
| **Research aims & objectives** | |
| Aims of the study | |
| Any further research questions addressed | |
| **Setting / context** | |
| Country in which study took place | |
| Study setting (e.g. rural, urban) | |
| Study date and duration | |
| Links to services / organisations | |
| **Sample** | |
| Sampling / recruitment procedures | |
| Sample size | |
| Age range | |
| Inclusion / exclusion criteria | |
| Gender identities | |
| Sexual identities | |
| Disability labels | |
| Living context | |
| Ethnicity | |
| Total LGBT identified in sample | |
| Total straight in sample | |
| Total undefined | |
| **Design & methodology** | |
| Study design | |
| Method of data collection (and by who) | |
| Number of times interviewed | |
| Length of interview | |
| Data analysis | |
| User/carer/stakeholder involvement in study design | |
| **Theories & concepts** | |
| Theory referred to or concepts | |

| **Findings** | |
|---|---|
| Themes listed | |
| Relevant quotes to evidence themes | |
| Ideas mentioned but not as themes | |
| Conclusions | |
| Implications for research | |
| Implications for clinical practice | |

## Appendix L

## Researcher's Epistemological Position

The researcher's understanding and definitions of sexuality and intellectual disability (ID) are described here to demonstrate transparency in how they have influenced this project. The researcher's understanding of sexuality evolved largely via personal experience. Since starting the project and further exploring his own and others' perceptions of sexuality and ID, the researcher's epistemological position has continued to develop. There is an element of fluidity, therefore, in the researcher's epistemological position.

The researcher understood the concept of intellectual disability as the label given to particular aspects of brain development and function (influenced by both genetics and environment) which naturally vary widely in the general population (normal variation) and which are considered disabilities by virtue of the value judgements constructed in given social and historical contexts. This could be considered a largely social model of disability with some biological elements.

The researcher understood the concept of sexuality to be naturally predetermined potentials for romantic and sexual affiliations which vary widely in the general population (normal variation); the realisation of these potentials gives rise to individuals' sense of sexuality. This could be considered a fairly essentialist perspective. How sexual identity is expressed, however, is influenced by social context. Categorical definitions (for example, gay/ lesbian, bi, straight) can be reductionist and misleading in that they do not acknowledge the diversity of people's experiences. The researcher leans towards social constructivism in understanding world experiences, however, he believes there is often

value in bio-psycho-social perspectives. It might be that the researcher's personal connection to (non-heterosexual) sexuality issues influenced his essentialist position, while professional experience of ID influenced a social constructivist understanding. The researcher generally does not advocate for positivism in understanding human experience.

**Impact of the Epistemological Position in this Project**

The researcher recognised the importance of using participants' own labels (sexuality and disability) in this project and endeavoured to do so where appropriate. Participants had self-disclosed ID labels to the LGBT service to gain access to the ID-LGBT group, and often disclosed LGBT labels to referring professionals (where they did not self-refer) to gain access to the LGBT service.

Standardised measures of IQ would not have been appropriate in this project as 'objectivity' was not an intended outcome (nor did the researcher believe it could be achieved regarding ID assessment). Rather, the subjective experience of participants was prioritised. IQ assessment would also have raised an ethical dilemma which could have had negative implications for participants: could ID-LGBT group members continue to attend if assessment suggested IQ was not within the range classified as ID? IQ is only one factor in assessment of ID and a full assessment would have been impractical, of little or no value and unnecessarily burdensome for participants.

Personal experience of coming out as an adult might have influenced the researcher's expectation that sexuality can be personally known and understood at a young age, irrespective of sexual experiences.

## Appendix M

## Rationale for Choice of IPA Methodology

The rationale for the methodological approach in this study was based on consideration of a range of qualitative methods.

IPA is suited to data from small and homogenous samples which enables detailed exploration of psychological phenomena. IPA privileges individuals' unique perspectives and does not seek objectivity. Participants make sense of their experiences and convey an interpreted account to the researcher, the researcher then interprets the account and creates a second order understanding of what the participant has said. Interpretation in data analysis follows a double hermeneutic process. Interpretations of a small part of the data can illuminate the dataset as a whole, creating new understandings of the whole which may further create a different understanding of the interpreted part.

The potential sample size in this study was restricted by recruitment from a small and unique ID-LGBT group. That the participants had access to such as group was rare and constituted homogeneity of the sample.

A grounded theory approach was considered less appropriate than IPA as theory development was not a research aim and a large enough population from which to purposively sample was unavailable. Thematic analysis was less appropriate than IPA as its focus is less interpretative and more descriptive. Narrative analysis was less appropriate than IPA as its focus is on socially contextualised storylines rather than the idiosyncratic aims of this study.

## Appendix N

## NHS Ethics Approval

**NRES Committee North West - Preston**
HRA NRES Centre - Manchester
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7818
Facsimile: 0161 625 7299

24 June 2013

Dr Beth Greenhill
Senior Clinical Tutor / Chartered Clinical Psychologist
University of Liverpool
D.Clin.Psychol. Programme, Division of Clinical Psychology, University of Liverpool,
Whelan Building, Brownlow Hill, Liverpool,
L69 3GB

Dear Dr Greenhill

**Study title:** **Being Out with a Learning Difficulty? An Interpretative Phenomenological Analysis of how people with access to a support group for lesbian, gay, bisexual or trans(gendered) people with learning difficulties experience the development of their sexual identities.**
**REC reference:** **13/NW/0379**
**IRAS project ID:** **124531**

Thank you for your letter of 17 June 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 29 May 2013

**Documents received**

The documents received were as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Covering Letter | | 17 June 2013 |
| Participant Consent Form | 2 | 13 June 2013 |
| Participant Information Sheet | 2 | 13 June 2013 |

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Covering Letter | | 03 May 2013 |
| Covering Letter | | 17 June 2013 |

| | | |
|---|---|---|
| Interview Schedules/Topic Guides | 1 | 01 May 2013 |
| Investigator CV | Dr Beth Greenhil | |
| Investigator CV | Dr Alex Cookson | |
| Investigator CV | Mr Dinwoodie | |
| Letter from Sponsor | | 12 April 2013 |
| Letter from Sponsor | | 01 May 2013 |
| Participant Consent Form | 2 | 13 June 2013 |
| Participant Information Sheet | 2 | 13 June 2013 |
| Protocol | 2 | 31 December 2012 |
| REC application | 3.5 | 07 May 2013 |
| Referees or other scientific critique report | | 29 January 2013 |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**13/NW/0379** **Please quote this number on all correspondence**

Yours sincerely

**Mrs Carol Ebenezer**
**Committee Co-ordinator**

E-mail: nrescommittee.northwest-preston@nhs.net

## Appendix O

### Participant Information Sheet

The participant information sheet is too large to include here in full. Sections of the document are included here for illustrative purposes. Only written material is included. The original document contained copyrighted photographs and images which the author does not have permission to publish. These images originally appeared to the left of the text.

This leaflet is about some **research**.

Research happens when we want to understand something better.

Research is how we find out answers to questions.

A **researcher** does research.

A researcher asks people questions to understand something better.

Then they can tell other people about it.

This helps more people to understand it.

This research is called

**Being Out with Learning Difficulties.**

This leaflet tells you about our research.

It will tell you why we are doing our research.

It will tell you how to join in if you want to.

Please do not make up your mind now.

Think about it before you say yes or no.

Talk about it to someone you trust if you want to.

## People doing the research

This is Rob Dinwoodie.

He is the researcher.

Rob goes to the University of Liverpool.

He is a **Trainee Clinical Psychologist**.

This means he is learning to be a **Clinical Psychologist.**

Clinical Psychologists help people.

They talk to them when they have a problem.

Clinical Psychologists also do research. This helps them understand how to help people.

This research will help Rob to become a Clinical Psychologist.

This is Beth Greenhill.

She is in charge of the research.

She is a Clinical Psychologist.

Beth works at the University of Liverpool.

Beth checks what Rob does.

She makes sure he does the research right.

If you want to ask Beth any questions you can telephone her.

Her telephone number is **0151 794 5534**.

Before any research is allowed to happen it has to be checked by a group of people.

The group of people is called a **Research Ethics Committee**.

The Research Ethics Committee makes sure the research is fair.

This research has been checked the Research Ethics Committee called NRES Committee North West - Preston.

They said it is ok for Rob to do this research.

If you are unhappy about the research, you can tell Beth Greenhill.

You do not have to tell Beth if you are unhappy about the research.

You can tell **PALS** instead if you want to.

PALS is the Patient Advice and Liaison Service.

They help people who are unhappy about research.

PALS telephone number is **0800 073 1106**.

| What we want to understand better |
| --- |
| We want to speak to people with learning difficulties who are lesbian, gay, bisexual or trans.<br><br>We want to speak to people with learning difficulties who are not sure if they are lesbian, gay, bisexual or trans.<br><br>Sometimes we say **LGBT** instead of lesbian, gay, bisexual or trans. |
| We want to know how people know they are LGBT.<br><br>We want to know if anyone helps people know if they are LGBT.<br><br>We want to know how people tell someone else they are LGBT. |

We want to know what is good and bad about being LGBT.

## Why we want to know

People with learning difficulties who are LGBT have not joined in much research before.

This means we do not know what is the best help to offer.

We hope our research tells us the best help to offer.

This might help us think of better ways to help people with learning difficulties who are LGBT.

## If you say yes to join in, this will happen:

You will have an **interview** with Rob.

He will talk to you and ask you some questions.

He will ask you about having learning difficulties and being LGBT.

The interview will last about one hour.

You will only have one interview.

You can stop the interview any time you want to.

Rob will record what you say.

## Appendix P

## Consent Form

The consent form is too large to include here in full. A section of the document is included here for illustrative purposes. Only written material is included. The original document contained copyrighted photographs and images which the author does not have permission to publish. These images originally appeared to the left of the text.

**Consent** means you can **say yes or no** to join in the research.

If you say yes, **tick the boxes** on pages 3, 4, 5, 6, 7, 8, 9, and 10, to show you say yes.

Then **write your name** on page 11, to show you say yes.

**It is ok to say no** if you want to.

Please do not say yes if you really want to say no.

Do not tick the boxes if you want to say no.

Even if you say yes now, **it is ok to change your mind** and then say no.

It is ok to change your mind at any time.

It is ok to change your mind for any reason.

| | |
|---|---|
| I have the leaflet called **What is it like to be LGBT and have learning difficulties.** | ☐ |
| I read the leaflet or someone helped me read it. | ☐ |
| I asked the questions I wanted. | ☐ |

| | |
|---|---|
| Rob answered all my questions. | ☐ |
| I know what the research is about. | ☐ |
| I can say no if I do not want to join in. | ☐ |
| I want to join in the research. | ☐ |
| Rob will ask me questions in an interview. | ☐ |

| | |
|---|---|
| Rob will record what I say.<br>I can ask Rob to stop the recording. I can ask for words to be changed. | ☐ |
| After the interview, Rob will listen to it again. He will write down everything I said. | ☐ |
| He will write about this in his work. | ☐ |

**Appendix Q**

**Interview Schedule**

# What is it like to be LGBT and have learning difficulties?

## Interview schedule

**Key objectives:**

1) To understand how participants experience their sexual identities;
2) To understand whether participants perceive themselves as being involved in a process of coming out;
3) To describe what participants perceive as:
   i. key facilitative personal strengths,
   ii. any functions of role models, and
   iii. key costs and /or benefits, of any decisions to come out.

| **Topics for discussion (questions)** | **Interviewer notes (prompts)** | **Timing (approx.)** |
|---|---|---|
| **1. Welcome and introduction to interview** | | **5 min.** |
| • Explain aim of interview:<br>- to learn more about what it is like to be LGBT and have learning difficulties.<br><br>• Remind of:<br>- Who researcher is (name, job etc.)<br>- Ok to have someone else present if wanted<br>- Confidentiality – won't discuss details of what you say with anyone else from ID-LGBT group<br>- Ok to stop/pause at any time for any reason<br>- Interview lasts up to one hour<br>- Permission to audio-record interview.<br><br>• Answer any questions before starting | | |
| **2. Introduction to the participant** | | **5 min.** |
| • Preferred name?<br>• How did you get here today? | Start with introductory questions that are simple to | |

| | | |
|---|---|---|
| • What else have you done today / plan to do later?<br><br>• Can you tell me a little about yourself?<br>• How old are you?<br>• Who do you live with?<br>• How long have you lived there?<br>• Where did you grow up? (Live as a child?)<br>• Do you have any family?<br>• Do you have a support worker?<br>• Do you have anyone else who helps you to do things? | answer – ice-breakers to facilitate participant to feel more comfortable talking in first few minutes. | |
| **3. Identity – sexuality and learning difficulties** | | **10 min.** |
| • Sexuality.<br>- When did you first hear the word lesbian / gay / bisexual / trans?<br>- Does that mean anything about you?<br>- Some people might say they are lesbian / gay / bisexual / trans – do any of these words describe you?<br>- Do you call yourself are lesbian / gay / bisexual / trans?<br><br>• Learning difficulties.<br>- When / how did you first hear about the ID-LGBT group?<br>- How long have you been coming to ID-LGBT?<br>- Do you come to the LGBT service for other kinds of support?<br>- What kind of things do you talk about in the group?<br>- What do you think about the name of the group?<br>- Some people do not like the name learning difficulties and some people do. What do you think about it?<br>- Does it mean anything to you / say anything about you? | | |
| **4. Coming out** | | **10 min.** |
| • If LGBT:<br>- Can you remember when you first knew you were L/G/B/T?<br>- Who did you tell first?<br>- What made you decide to tell that person?<br>- What helped you to tell that person? | | |

| | | |
|---|---|---|
| - Did anything make it hard to tell that person?<br><br>- Were you worried about telling anyone?<br>- Who were you most worried about telling?<br><br>- Is there anyone that you have not told?<br>- What makes it hard / stops you telling that person?<br>- What would make it easier to tell that person?<br><br>• Costs / benefits<br>- What was good about telling _____?<br>- What was bad about telling _____?<br>- Are you glad that you have told people?<br>- Do you wish you had not told some people?<br>- Is there anything good about being LGBT?<br>- Is there anything bad about being LGBT?<br><br>• Personal strengths<br>- What things do you do (or things about you, your personality, your good points as a person) that help you tell people you are L/G/B/T or come out? | | |
| **6. Role models** | | **10 min.** |
| • Before coming to ID-LGBT group, did you know any other people who were LGBT?<br>• Did anyone help you to know you are LGBT?<br>• Did anyone try to stop you being LGBT?<br>• Do you have any friends now who are LGBT?<br>• Do you know any famous people who are LGBT?<br>• What do you think about them being LGBT?<br>• What do other people say about it?<br>• Are any of your support workers (anyone who helps you) LGBT?<br>• What do you think about it?<br>• What do other people say about it?<br>• When you were growing up (as a child) did you know anyone who was LGBT?<br>• What did you think about it? (Was it a good thing or a bad thing that they were LGBT?)<br>• What did you think about LGBT people when you were growing up (as a child)?<br>• What did other people say about it? | | |

| **7. Participant advice to others** | | **10 min.** |
|---|---|---|
| • What would you tell someone to help them know if they are LGBT or not?<br><br>• What advice would you give to someone who thinks they are LGBT but have not told anyone yet?<br><br>• What kind of support / help do you think people (support services) should offer to people with LD who are LGBT?<br><br>• Is there anything that people should not do / stop doing if they want to help people with LD who are LGBT? | | |
| **8. Conclusions** | | **10 min.** |
| • Summarise key points of interview.<br>• Anything we didn't speak about that you think we should have? (Missed out anything important to our talk?)<br><br>• Wellbeing check.<br>- How are you feeling now that the interview is almost over?<br>- What are you going to do after the interview?<br><br>• Feedback options.<br>- Option for feedback after recommendations written.<br>- Like to meet with me again early next year when the research has ended so I can explain what I learned from the research? (Don't have to decide now, can always change your mind later.)<br><br>• Thank you for participating.<br>• End of interview. | Final check if interviewer understood correctly and covered all topics important to participant. | |

## Appendix R

## Reflective Diary Excerpt

**Reflecting on sexuality disclosure in the interview process:**

No participant asked me about my own sexuality. Maybe they assumed I was gay? – the usual policy of the LGBT service is that outside professionals have to be LGBT or somehow approved to be LGBT-affirmative. Maybe staff told them I was gay so they didn't have to ask as they already knew? I was expecting at least someone to ask / check if I was gay in order to feel comfortable talking about their own personal experiences of sexuality. Insider vs outsider. Could this be the influence of me being in a position of relative power – they didn't feel able to ask me? Maybe if they assumed I was gay or gay-affirmative either way it wouldn't matter what my sexuality is – because I would be in a 'helping' role? Are participants used to people having a position of authority in their lives and they feel unable to question it? Trusting the provision of support from the LGBT service – vetting me before being allowed in?

**Reflecting on the hermeneutic circle in data analysis:**

Why would 'Kenneth' say 'it just didn't work out' about his marriage ending in divorce – because he'd already told me he was gay and that the marriage ended when his wife found him in bed with a man?

The word 'just' revealed the inevitable and natural aspect of sexuality 'just' being like that. This made more sense of 'Kenneth's' comment. It didn't work out because he is 'just' gay and even when getting married it was probable that he would have struggled to change his gay feelings because he is 'just' gay.

## Appendix S

## Annotated Transcript Sample from 'Kenneth'

| Emergent themes | Line | Original transcript | Coding / notes |
|---|---|---|---|
| | 141 | you know and that. I found out a few months later when she went | So for a few months assume he blamed himself for the breakup of the relationship? |
| | 142 | back to live in [PLACE] with her Mum because she moved to | Neither him nor her could tell each other their real sexuality – but both married. |
| | 143 | [PLACE], I found out that she was a lesbian [LAUGHS]. So a sort of | *Laughs* – with relief that she was a lesbian (i.e. it's ok for him to be gay because she was a lesbian?) or to ensure my reactions are positive (does he expect negative reactions from me to hearing his circumstances- think I might judge him?)? |
| | 144 | weird relationship. | *Weird relationship*. Did he feel weird in the relationship, feel weird because of the circumstances? Knew it wasn't right for him? |
| | 145 | **I:** How did you find out? | |
| | 146 | **PT:** Well her friend, who I still see, she still sees and keeps in | Wife did not say she was a lesbian, a friend told him. No contact anymore? |
| | 147 | contact and she told me, you know, so it was weird like but you | *It was weird. But you know* – minimising the weird feeling? |
| | 148 | know, so that's how I found out and that. | |
| | 149 | **I:** Had you known her, how long had you known your fiancé at that | |
| | 150 | time? | |
| | 151 | **PT:** Oh for a while from when I was 16 when we went on a what do | Met on a work training scheme age 16. |
| | 152 | you call it a YGS then you know when you went on them and you | |
| | 153 | sort of got paid like 25 quid which was a lot then, you know, so it | |
| | 154 | was sort of like that you know, that's how I met her and that. | |
| | 155 | **I:** And you started to say before about you, I think I am right in | |
| | 156 | remembering you said you got married because you didn't want to | |
| | 157 | be gay, is that what you said? | |
| Because some of my family are anti-gay – not wanting to be gay influenced by family. | 158 | **PT:** Yes, yes 'cause some of my family are sort of like [PAUSE] anti- | Did not want to be gay because some of his family were anti-gay at that time. *Pause – unsure how to say it? Hesitant saying anti-gay*. Influence of family on feeling able to come out, seek support for his sexuality needs. Tried to make himself not be gay by getting married. *Are anti-gay – present tense.* |
| But they're not now because we've got more gays in the family – changed family attitudes. | 159 | gay you know so, I didn't want to be, but they're not now because | *Family* – immediate or wider family? Influence of the whole family, not just certain members? |

| | | | |
|---|---|---|---|
| | 160 | we've got more gays in the family. Got a cousin who's a lesbian, | More acceptable to be gay now that there are more gays in the family. Higher visibility of gay people / awareness that people are gay in the family makes it more acceptable for him to be gay? Normalising effect for the family of knowing gay people personally. |
| | 161 | and I've got a younger cousin that's just came out so they're not | |
| | 162 | sort of like, but they're quite funny because they'll go oh er ah | Brushed over them previously being anti-gay to tell me about how funny they are now. Keen to give impression of family as accepting of him – is this the view of them he is trying to hold/preferring to hold as a way to manage the conflicting reactions from them? If they weren't accepting when he first came out why are they now – his sexuality hasn't changed? What impact did their initial reactions have on him and how he now involves them in his sexuality – seems he keeps them / they keep it at a distance through use of humour and superficial engagement. His sexuality is still not a 'safe' or comfortable topic despite their 'acceptance'. Suspect he is aware of this on some level as he does not like to push it in their faces, and he relies on LGBT LD group for sexuality support so he doesn't have to involve his family. using humour. |
| | 163 | that'll suit you [PT NAME] and I say pink handbag there but you | |
| They'll say it in a funny way so now it doesn't bother me – humour and sexuality. | 164 | know they'll say it in a funny way as not as a, so now it doesn't | Family make reference to his sexuality in a funny way, so it doesn't bother him now. Previously was bothered with how the family engaged about his sexuality. Is that the only time they talk about his sexuality – in a joking way, not taking him or his sexuality seriously? Do they talk about straight family members in the same way? If only discussed as a joke then although he might not take offence it positions his sexuality as separate from the rest of the family who are straight and as a something not to be taken seriously? Or if the family seem to use humour to defuse potentially negative feelings (as he seems to have done several times in the interview) then it implies that his sexuality is associated with some negativity within the family and he engages in such banter as he has no other options/ways of discussing his experiences? |
| I do get hassled now and again where I live – abuse. | 165 | bother me. But I do get [PAUSE] hassled now and again where I | Hassled where he lives. *Pause – cautious description?* |
| | 166 | live and that you know, I get skitted you know. | |

## Appendix T

### Example of List of Emergent Themes for 'Kenneth'

List of emergent themes which have been clustered (on conceptual similarity) and given a cluster name (in bold). Line numbers follow each them to link to transcript text.

**They think it's wrong because we don't know our own minds - Denied a sexuality or taken advantage of due to LD**

They think it's wrong because we don't know our own minds - Being denied a sexuality 492, 574

When they find out you've got a learning disability they back off – rejection due to LD 490, 493, 564, 572

I can be what I want with them because they think I'm funny – not taking his sexuality seriously. 349

I seem to meet divvies – being taken advantage of due to LD 486, 487, 493

**Until they hurt me that's when I do something about it - Physical vs emotional pain**

Until they hurt me that's when I do something about it – physical pain priority over emotional 188, 204

Now I go 'oh forget it' because it hurts – prioritising physical over emotional pain. 365

I used to have to drink a lot of water because my voice hurt that much – accepting physical pain to conceal sexuality. 362

Emotional pain expressed physically / self-harm through drinking when depressed. 528

**At least we don't live in Russia vs It doesn't bother me really but sometimes it does - Sense of Protection / Resilience vs Feeling stuck / Hiding emotions**

**(Resilience vs feeling stuck)**

You've just got to get on with it - Feeling stuck / coping / resilience 21, 169, 170, 180, 186, 200, 202, 223, 240, 582

I can be what I want with them because they think I'm funny, that's how I deal with it now - Humour and sexuality 164, 348

**(Sense of protection)**

At least we don't live in Russia - Sense of protection 70, 85, 209, 225, 230, 232, 236, 449

**Family is all you need vs I hate to push gay things in their face – navigating family involvement (support vs intrusion/control)**

Family is all you need - Family involvement in his sexuality / life 65, 159, 158, 281, 499

I can be what I want with them because they think I'm funny, that's how I deal with it now - Humour and sexuality 164, 348

I can be what I want with them because they think I'm funny – not taking his sexuality seriously. 349

I hate to push gay things in their face – not involving family with sexuality issues 270, 271, 278, 283, 760, 770

**I actually got married because I didn't want to be gay - Sense of himself as gay not being ok / unacceptable prior to coming out**

I actually got married because I didn't want to be gay – not wanting to be gay 112, 140, 404

I had to make my voice deeper – concealing sexuality 328, 361, 392, 438

They probably wouldn't be my friend anymore - Fear of coming out 438,443, 470

**I just be myself now – sense of himself as being ok / acceptable since coming out**
I just be myself now - Coming out to be himself 327, 342
I was quite shy when I came out so they've helped me a lot – LGBT LD support. 86
If someone says are you gay I go yes have you got a problem with it – confidence in who he is / defending himself. 89
I felt fine because he was ok with it – positive response to coming out 448, 475

**You've got gaydar - Knowing sexuality – self and others**
Oh that boy's nice - Knowing his sexuality 403, 429, 432, 650, 651
The way they mince – signs of gay sexuality 332, 361, 592, 596, 604
You've got gaydar – knowing someone is gay 585, 96, 599, 611
I always knew I was gay but I didn't know the name of it – not having the words for his sexuality.644, 650
I would know they've got a learning disability the same as if someone's gay – knowing someone has LD. 587

**I want a relationship but I'm scared in case they get me into trouble - Desire for a partner vs fear of getting hurt and lack of opportunity**
So you can go out for fancy meals - Desire for a partner / romance 50, 476, 535, 537, 549, 680
I want a relationship but I'm scared in case they get me into trouble - Fear of relationships 503, 518
You like to be honest with them so you tell them – naming LD to potential partners. 577
You can't exactly come dating here - Lack of LD LGBT dating support 707, 712
They are always bitching – uncomfortable in non-LD LGBT group. 731

**She was asking me questions and I couldn't tell her - Barriers to coming out (LD and indirect questions)**
She was asking me questions and I couldn't tell her – difficulties coming out 113, 115, 375
I'm not a good speller so I cut it out of the paper - Coming out despite barriers 116, 319

**Sex with your mate can ruin your friendship - Relevance of sex** 379, 429, 678

**Sometimes they call you a faggot or a puff – experience of abuse** 165, 172, 173 247

## Appendix U

## Section of Themes Table for 'Kenneth'

| Theme cluster name | Theme | Page number | Line number | Keyword / quote |
|---|---|---|---|---|
| **They think it's wrong because we don't know our own minds - Denied a sexuality or taken advantage of due to LD** | They think it's wrong because we don't know our own minds - Being denied a sexuality | | 347 | My Auntie and my cousin, you know the way girls go "oh he's nice", I go "oh yes" you know so I can be what I want you know with them because they think I'm funny you know when I come out and go, not you know because I'm gay but the way I go they go "oh yes he's nice" I go "oh yes I know what you mean" so I can be as I am you know what I mean, so you know it's, that's how I deal with it now. |
| | I seem to meet divvies – being taken advantage of due to LD | | 483 | I: And you met him through the heart to heart column?<br>PT: Yes, the [NEWSPAPER] so you know so I have had relationships but not counting the one out of the heart to heart, he's great, but the I seem to meet divvies you know. People that hurt me, because I've had a few [PAUSE] and it's because I'm classed as gullible, I think they sort of like play on it, because some people if you've got a disability, learning disability and you're gay, I think in my head, and a few of the others do, think when you've got a disability they don't want to know you. Because they think it's wrong, you know what I mean, we don't know our own minds so you know I think they sort of like play on it you know or they don't want to know you, because I mean I've had a few and I've had bad relationships and that where they've hurt me in the past you know so. Not hurt me as punched me you know, they've left me, or they've done stuff like [PAUSE] they've took the micky out of me or you know or misled me or stuff like that you know so. |
| | | | 561 | because we've got, how can I explain, a learning disability which you know learning stuff and that I mean, I've got that, I'm epileptic, bad on my feet you know so that and a physical disability so but when you've got all that people don't want to know you. |
| | | | 567 | I: Yes, and what do you feel about exactly what you've just said then when you've got disabilities and you feel like people don't want to know?<br>PT: Well they, when they sort of like go on the gay scene and you start meeting people and you're talking and doing and they like you but then when they find out you've got a learning disability, they |

| Theme cluster name | Theme | Page number | Line number | Keyword / quote |
|---|---|---|---|---|
| | | | | sort of like go oh yes, back off, you know, because they think it's wrong because we don't know our minds if we are gay or straight or you know what I mean but… |
| **Until they hurt me that's when I do something about it - Physical vs emotional pain** | Until they hurt me that's when I do something about it - Physical vs emotional pain | | 179 | I: How do you feel about it when people they say those things?<br>PT: It's, it hurts but I don't let it, let people know it's hurt me do you know what I mean.<br>I: How do you manage to do that?<br>PT: Just block it out or as I say turn my hearing aids off and I don't hear that much then you know, 'cause when I turn my hearing aids off and you are talking to me I only hear, you know, mumbling so I mean it could be anything you've just got to get on with it you know. I mean they say that thing that [PAUSE] something stones a thingy hurts me but names don't so I just think of that, until they hurt me that's when I do something about it but.<br>I: When someone physically hurts you?<br>PT: Yes |
| | | | 202 | know it doesn't bother me really but sometimes it does you know when you're feeling down, you know, that's when it does hurt and that, but as I say you've just got to get on with it. Until they start hurting me as I say that's when I'll do something. |
| | | | 356 | I: Yes, and you said that you tried to make your voice deeper?<br>PT: [SPEAKS IN DEEP VOICE] Yes like the way I'm talking now [LAUGHS] [NORMAL TONE] and it hurts.<br>I: Does it.<br>PT: You know when you're talking deep like and, I used to do my own discos, I used to talk in a deep voice but project my voice [SPEAKS IN DEEP VOICE] so I would talk deep like that and I use to have to drink a lot of water because me voice hurt that much because I was talking in a deep voice all the time, so you know but now I just go "oh forget it" because it hurts you know what I mean? |
| | | | 526 | it sort of like<br>upsets me when they you know when you're in a relationship and they leave. Like when I was with someone I felt that depressed I |

## Appendix V

## Explanation of Audit Trail

The audit trail through this research was facilitated by accurate record keeping and consisted of:

- Supervision notes
- Research proposal
- Interview schedule
- Audio-recorded interviews
- Reflective diary
- Annotated transcripts
- Lists of emerging themes
- Groupings of emerging themes/refining themes
- Tables of themes for participants linking themes to quotes
- Draft reports
- Final report.

All data are stored on the data CD held by the data custodian and are available upon request.